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ABSTRACT

These two journal issues discuss topics relating to the physical and health disabilities of children and adults. The first issue contains the following articles: (1) "Position Statement on Specialized Health Care Procedures," by the Council for Exceptional Children's Division on Physical and Health Disabilities that calls for all teachers to maintain a safe, healthy environment for their students and to view specialized health care procedures as self-help skills or independent living skills that students should be taught to promote their independence; (2) "Teaching Reading to Students with Severe Speech and Physical Impairments Using the Nonverbal Reading Approach" (Kathryn Wolff Heller and others); (3) "Vermont's Guidelines for Related Services: Supporting the Education of Students with Disabilities" (Michael F. Giangreco and others); and (4) book reviews of "Students with Acquired Brain Injury: The School's Response" edited by Ann Glang, George H. S. Singer, and Bonnie Todis; "Living with Spina Bifida: A Guide for Families and Professionals" by Adrian Sandler; "Caring for Children with Cerebral Palsy: A Team Approach" edited by John Paul Dormans and Louis Pellegrino; and reviews of videotapes on students with asthma, diabetes, and acquired immune deficiency syndrome. The second issue contains two articles that explore the role of the educator as a leader of multidisciplinary teams: (1) "Feeding Students with Disabilities: An Holistic Approach for Educators" (Dianne Koontz Lowman) and (2) "Exploring Role Release in the Multidisciplinary Team" (Bonnie L. Utley and Mary Jane K. Rapport); and a third article, "Review of Research and Conceptual Literature on the Use of Botox with Individuals with Cerebral Palsy and Related Spastic Disorders" (S. John Obringer). Book reviews include "The Educator's Guide to Feeding Children with Disabilities" by Dianne Koontz and Suzanne McKeever Murphy, "Collaborative Teams for Students with Severe Disabilities: Integrating

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Therapy and Educational Services" by Beverly Rainforth and Jennifer York-Barr; and "Children with Facial Difference: A Parent's Guide" by Hope Charkins. (Articles include references.) (CR/LC)

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Physical Disabilities: Education and Related Services, Fall 1999-Spring 2000

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Barbara J. Kulik, Editor

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SPECIAL REPORT

POSITION STATEMENT ON SPECIALIZED HEALTH CARE PROCEDURES

DPHD Critical Issues and Leadership Committee

An increasing number of students require specialized health care procedures during school hours. Procedures such as tube feeding, clean intermittent catheterization, suctioning, and ventilator management are becoming more common place in the school setting. Who actually performs the procedures and is responsible for them being correctly implemented varies across school districts and states. Although consensus can be difficult to reach regarding who should be performing these procedures at school, consensus can be reached regarding other critical areas surrounding specialized health care procedures. Two critical areas have been identified by the Critical Issues and Leadership Committee of the Division for Physical and Health Disabilities. These are as follows:

First and foremost, all teachers need to maintain a safe, healthy environment for their students in collaboration with others in the school. This includes learning about their students' specific physical and/or health impairments, physical health care procedures, and treatment regimen. Teachers should know the major problems and emergencies that could arise with each student. There should be a plan in place to know how to respond should a problem occur. Teachers should also know general safety skills such as universal precautions, general first aid, and CPR to promote a safe, healthy environment.

Second, specialized health care procedures should be viewed as self-help skills or independent living skills which students should be taught to promote their independence. Specialized health care procedures and other health management skills should be considered for IEP goals and objectives. These IEP objectives could target independent performance, partial participation, directing someone else in performance, or knowledge of the task. It is the educational team's responsibility to consider how students can participate in their own self-care. When the team decides to target this area of instruction, teachers of students with physical and health disabilities are responsible for designing and implementing curriculum and instructional strategies for medical self-management procedures by students with specialized health care needs (The Council for Exceptional Children, 1998). The plan for, and establishment of, instruction in the area of medical self management skill development must include input from appropriate health care specialists (such as nurses, OTs & PTs). Teachers of students with physical and health disabilities are responsible for providing expertise in the area of instructional strategies and adaptations to promote student learning of these procedures. Even when health care personnel are responsible for performing these procedures, teachers must work closely with them, providing appropriate instructional strategies, error analysis, and correction procedures.

In summary, teachers have a responsibility to develop knowledge and skills regarding their students' health care needs. Maintaining a safe, healthy environment and viewing their students' specialized health care needs as potential educational targets requiring the teacher's expertise in instruction, are two issues that require more attention and commitment.

REFERENCE

The Council for Exceptional Children (1998). What every special educator must know: *The international standards for the preparation and licensure of special educators, Third Edition*. Reston, VA: Author.

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TEACHING READING TO STUDENTS WITH SEVERE SPEECH AND PHYSICAL IMPAIRMENTS USING THE NONVERBAL READING APPROACH

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ABSTRACT

There is a national concern regarding the poor reading skills of students with severe speech and physical impairments. Difficulty in reading may partly be attributed to the lack of information regarding the strategies needed to modify an effective reading program utilizing adaptations and technology for this population of students. This study investigated the Nonverbal Reading Approach of internal speech, diagnostic distractor arrays, and error analysis, within a Direct Instruction systematic reading curriculum. Case studies of three students demonstrate the use of this reading approach, with the concurrent use of assistive technology to improve reading.

One of the most critical problems in the field of physical disabilities is effectively teaching reading to students who were born with physical disabilities that impede speech and movement. These students, having severe speech and physical impairments (SSPI), typically exhibit significant reading and

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Authors' note: Special thanks to Sharon Hunt for her contribution to this project.

writing difficulties (Berninger & Gans, 1986; Pierce & McWilliam, 1993; Smith, Thurston, Light, Parnes, & O'Keefe, 1989). Their reading skills are poorer than would be predicted based on intelligence and educational levels (Foley, 1993; Seidel, Chadwick, & Rutter, 1975), with deficits continuing into adulthood (Smith et al., 1989). Given the severity of this problem, a call for more research in the area of literacy skills has come from researchers, teachers, parents, and national organizations (Foley, 1993; National Critical Issues and Leadership, Division for Physical and Health Disabilities, 1996).

Many factors contribute to literacy difficulties for students with severe speech and physical impairments. Lack of experiences is one such contributing factor. Students with SSPI typically have more limited broad experiences, language experiences, and literary experiences which can interfere with literacy development. Obtaining broad experiences may be limited due to difficulty ambulating to explore interesting items or activities (Blischak, 1995), or due to a lack of first-hand knowledge of common places, such as a mall, because of transportation problems. Common activities, such as sitting on the grass and observing ants crawling around, may be missed. Difficulty manipulating objects may result in inaccurate perceptions or missed perceptions regarding their properties. This lack of broad experiences can interfere with comprehension of literacy activities. Usual language experiences may also be missed due to a lack of speech, restricted use of selecting pictures/symbols, slow rate of communication exchanges, and alterations of communication patterns which are often constraints from physical disabilities (Fried-Oken, 1988). Lack of typical expressive language events may also interfere with literacy development (Stratton & Wright, 1991). Reduced parental expectations and differences in literacy experiences may also affect literacy development of children with SSPI (Koppenhaver, Evans, & Yoder, 1991; Light & Smith, 1993).

A second factor affecting literacy is the restricted participation in typical literacy activities. Students with SSPI can not understandably read aloud, retell stories or say the sounds of the letters while decoding words (i.e., sound out words). Often participation in literacy events such as providing an original sentence in class to be part of a chart story is not possible. This is compounded by the difficulty these students may have in asking questions regarding literacy experiences. Students may not be able to ask questions about sounds, words, or stories. This not only results in unanswered questions, but can interfere with student learning, monitoring student progress, and typical literacy development (Blischak, 1995; Katims, 1993), Although having an augmentative communication (AAC) device will help students participate in literacy experiences, the AAC device may not be sufficient due to lack of mastery of the AAC system, lack of vocabulary, or inability to spell out words or questions when that skill is not yet in the student's repertoire.

The third factor affecting literacy is that motoric constraints may interfere with accessing written material and with writing. Students with physical disabilities may be unable to independently retrieve and manipulate books; this may decrease their contact with books. When a book is retrieved for a student, the problems of correctly positioning the book so it can be seen and having the child correctly positioned for optimal contact with the book may not be addressed. Once the book is in position, many students cannot handle books independently; that is, they may not be able to turn pages, indicate when they are ready to turn a page or go back to a previous page, or keep the book in its optimal position (Light & Smith, 1993). Without proper positioning and assistance, literacy experiences are lost. In addition, some students may have little prior experience scribbling, writing, or composing due to the severity of their motoric impairments or inadequacy of assistive technology. This also impacts literacy.

Students with SSPI have additional problems which can interfere with literacy. These include increased absenteeism; lack of attending to the reading task due to problems with pain, discomfort, or fatigue; additional physical or sensory limitations interfering with the task; and medication or treatment effects (Heller, Alberto, Fomey, & Schwartzman, 1996). Perceptual deficits (visual and auditory), language deficits, poor self-esteem, and passive learning patterns may also cause difficulty in reading (Smith, 1992; McNaughton, 1993).

Although the research on teaching reading to the SSPI population is limited, some helpful strategies have been employed. Those associated with literacy acquisition include being in home and school environments with large amounts of reading and writing material, having experiences with print, being read to by others and seeing text as it is read, hearing books on tape, having high parental and teacher expectations, and being personally motivated (Koppenhaver et al., 1991). Students' graphic representational systems used for their AAC devices may be used to assist with literacy acquisition (McNaughton, 1993) as well as in answering questions, spelling, and composition. Computers may be used to promote literacy through the use of educational software that "reads text aloud", as well as other software programs that develop decoding and encoding skills (Foley, 1993; Steelman, Pierce, & Koppenhaver, 1993).

Although reading skills develop in some individuals with SSPI (Berninger & Gans, 1986; Blischak, 1995; Foley, 1993; Smith, 1992), efforts to teach literacy skills to many students with severe speech and physical impairments have been less than successful (Berninger & Gans, 1986; Smith et al., 1989). Sometimes incorrect techniques are used. For example, asking the student what sound the "b" makes and having him point to a phonetic symbol on an auditory output device which produces the correct sound for him may assess his knowledge of the symbol, not his knowledge of its sound. If adaptations are not made to promote active student participation in the reading lesson, the development of skills will be impeded. Teachers may lack knowledge of research based strategies available in meeting students' needs. This is supported in one national survey which found that none (0%) of school systems' directors felt that their special education teachers were well prepared to teach reading to nonverbal students (Heller, Fredrick, Dykes, Best, & Cohen, 1999).

Direct Instruction. One literacy approach that is promising in terms of its adaptability for the SSPI population is Direct Instruction. Direct Instruction (DI) is "a systematic approach to the design and delivery of a range of procedures for building and maintaining basic cognitive skills" (Becker, 1992, p, 71). A basic assumption of DI is that all children can learn and if they do not, it is because they have not been taught well. It is the instruction that is faulty, not the students. If the instruction is faulty, it is because the communication is flawed; therefore, lessons are developed based on logical analyses of what is to be taught (Binder & Watkins, 1990). A Direct Instruction approach utilizing phonic and structural analysis was selected because it avoids the pitfalls of whole language approaches which assume that the student has attained a high level of mastery of the forms and functions of language and has a rich experiential language base for emergent literacy development. This assumption can not be made for students with SSPI. It ignores the differences in broad experiences, linguistic competence, literary experience, and physical ability which influence the process of learning to read (Foley, 1993). An approach that systematically and explicitly teaches reading skills, such as Direct Instruction, does not make the same assumptions as whole language approaches and instead provides students with a strategy to read unknown words and acquire new vocabulary independently, teaching generalizable skills for decoding unknown words (Jorm & Share, 1983; Vandervelden & Siegel, 1995).

Nonverbal Reading Approach. In order to effectively use a DI program, or any reading approach with students with SSPI, instructional modifications are necessary. One method is the Nonverbal Reading Approach which uses internal speech, diagnostic distractor arrays, and error analysis, in conjunction with specific adaptations and assistive technology. When students are not physically able to verbalize phonemes while sounding out words, they may be taught to use internal speech (Bigge, 1991). Internal speech is the process of silently speaking to oneself. Since research demonstrates the development of sound-blending skills in the absence of speech production abilities (Smith, 1989), it is quite likely that students can be taught to use internal speech to promote phonetic reading skills.

Since these students are unable to verbally produce their answers, they need to be given an array of choices from which to select their answers to the teacher's questions. Student choices from the array should indicate that the student does or does not know the correct answer. In addition, if the student does not know the answer, the selection from the array indicates the student's misunderstanding and what needs further instruction. A distractor array is a list of alternative choices provided to the student, either orally, or in writing (on paper, computer or AAC device). Distractor arrays are diagnostic when the alternative choices are carefully selected to include the correct answer and two or more additional items that can indicate a student's misunderstanding. For example, if the student is learning the word, "ball" and the choices are "bill," "ball," "doll,"and "bat" and the student chooses "bill," the error indicates that the student knows the first and last consonant, but not the vowel. If the student chooses the word "bat", it indicates that the student knows the initial sound and/or consonant, but not the ending. If the student chooses "doll" it indicates that the student does not know the beginning sound or vowel. A well constructed diagnostic distractor array will target the errors the student has been found to make. These diagnostic distractor arrays will help determine if the student is really reading the word. Analysis of the errors will enable the teacher to determine the student's specific problems and provide appropriate remediation. Poorly constructed distractor arrays provide little information and can give the impression that the student knows the word, when, in fact, the student does not. For example, if the student is learning the word, "ball" and the choices are "cat" "ball," "dog," and "tree," the selection of the word "ball" only tells us that the student can accurately select the correct first letter (b) of the word, but may not know the word "ball" from the word "big."

Another aspect of the Nonverbal Reading Approach is the use of assistive technology to assure proper assessment, instruction, comprehension, and practice of target reading material. This is often made difficult not only by the severe speech and physical impairments, but also by the accompanying disabilities often found in this group of individuals, such as mild mental retardation, perceptual problems, and visual impairments (Heller et al., 1996). Therefore, assistive technology selection must take into account physical and sometimes cognitive and visual limitations. The approach may include the use of augmentative communication devices, devices to allow access to choices, and computer adaptations to facilitate responses. Each of these must be individually selected and assessed as to its accuracy and effectiveness in facilitating the reading process.

The purpose of this study was to examine the use of the Nonverbal Reading Approach with Direct Instruction to increase students' reading ability. Three case studies are examined using this approach with individualized adaptations and assistive technology.

METHOD

PARTICIPANTS

Three students with SSPI who were identified as having difficulty reading were selected for this study. These students met the criteria of: a) having severe speech and physical impairments, b) being able to see print or enlarged print, c) having mild mental retardation to no cognitive impairment, d) having letter-sound correspondence of most of the alphabet, e) having an inability to decode unknown words phonetically, f) being a candidate for conventional (academic) literacy instruction, and g) having reading skills below the second grade level.

The three students who were selected for this pilot study are described in Table 1. The first student, Mary, is a 15 year old young woman with cerebral palsy. She is educated in a self-contained orthopedically impaired class in her local high school. Her mixed cerebral palsy has resulted in an inability to vocalize except for an "aahh" sound, but she recently began communication with a DynaVox2 (See Appendix) which she accesses by pointing. Her mother and sister read books to her frequently, which she enjoys.

The second student, Nancy, is almost 22 years old and has severe cerebral palsy and legal blindness. She is educated in a self-contained orthopedically impaired class. Now that she is in her final year of school, her mother wanted her teachers to try again to teach her to read and has made this the primary goal on her IEP. Nancy's severe mixed cerebral palsy restricts her movement, but allows her to verbalize approximations of several words and word sounds. She uses her Liberator (See Appendix) for communication with direct select by pointing to combinations of symbols or letters. However, she is unable to see the written message on the AAC display, due to her visual impairment.

TABLE 1.
Participants

	Student 1 "Mary"	Student 2 "Nancy"	Student 3 "Ned"
Disabilities	Spastic athetoid quadriplegia cerebral palsy Seizure disorder	Spastic/athetoid quadriplegia cerebral palsy Legally blind	Holt-Oram Syndrome with absence of both forearms and upper arms Asthma
Age	15 years, 1 month	21 years, 11 months	8 years, 3 months
Cognitive*	mild to moderate range (TONI-2: < 57 quotient)**	mild mental retardation***	mild mental retardation Kaufman-62
Placement	OI classroom Self contained	OI classroom Self contained	OI class- 2 segments First grade classroom
Speech	anarthria makes few sounds	severe dysarthria voices a few words/sounds	anarthria
Hand Function	5 second delay pointing Can point left to right	Up to 20 sec. delay pointing Can not point left to right without withdrawing hand	No hand function Toe points
Mobility	self propelled electric wheelchair	self propelled electric wheelchair	self propelled electric wheelchair
AAC	DynaVox2	Liberator	Macaw Yes/no switches

*Scores for Mary and Ned are thought to be somewhat depressed, due to lack of life experiences an difficulty finding an appropriate tool to measure IQ.

**TONI-2- Test of Nonverbal Intelligence

***Psychological report stated possible mild mental retardation to normal intelligence. No IQ score available.

The third student, Ned, is 8 years old and has Holt-Oram syndrome which has resulted in limited digits (fingers) being connected to the upper arm/shoulder area. He is also nonverbal and uses an electric wheelchair. He is in a regular first grade class with two periods of support from the special education teacher certified in orthopedic impairments and a full time paraprofessional assigned exclusively to him for the entire day. He is nonverbal, but has "yes" and "no" switches positioned at either shoulder which he activates by moving from one side to the other. He currently communicates with a Macaw (See Appendix) by pushing the display with his left toe and he can independently turn the display pages with his toe. He also uses eye gaze and is beginning to type his name and phone number on the computer using an alternative keyboard (IntelliKeys) (See Appendix).

SSPI LITERACY PROFILE

Before beginning instruction, the SSPI Literacy Profile which describes the student's current level of functioning in all areas affecting reading and reading instruction was developed. Information comprising the SSPI Literacy Profile was obtained through questionnaires to teachers, parents, and related staff, and through observation and testing. As seen in Table 2, the main sections included: communicating responses, physical efficiency areas (Heller, D'Andrea, & Forney, 1998), literacy functioning areas, and individual considerations. The results of the assessments performed on each student are summarized in Table 3.

Mary's SSPI Literacy Profile shows that she had many strengths across the major areas. Compared to the other students, she had the most motoric skills and awareness of print. She had an accurate means of response with pointing and gesturing yes/no. She just began learning her DynaVox2 system at the beginning of the study, and vocabulary was added to allow her to actively comment and question during her reading lesson (e.g., phrases were added such as "I understand," "I don't understand," "repeat that," "I need a break," "I need help with this word," "I'll be teacher and ask you," "what does this mean?"). Last school year and the first few weeks of the new school year, Mary received reading instruction with the Edmark Program (a functional literacy program using sight words rather than phonics). Minimal progress was reported for the last school year using this program and no progress was reported as occurring for the three weeks she had been in school this year. She was able to identify words and was assessed as being on the kindergarten level of reading with the Peabody Individual Achievement Test-Revised (PIAT). Mary did not easily fatigue during instruction, but she was very distractable and went off task easily.

TABLE 2.
SSPI Literacy Profile

SSPI Literacy Profile Areas
Communicating Responses
Means of response
AAC system (include access, symbol system, accuracy, fatigue, number of symbols in device, number symbols knows well, frequency of use)
Vocabulary on AAC (ask questions)
Computer use
Physical Efficiency Area
Body position, posture, use of two hands, finger/hand position, arm/hand movement, tactile perception, endurance
Placement of material for visualization, range of motion
Optimal number of items in array
Literacy Functioning Areas
Past reading attempts, adaptations, and targeting past difficulties
Visual memory and linguistic abilities
Reading skills
Book concept
Phonemic awareness
Orthographic awareness
Alphabet (letters, letter-sound knowledge)
Phonetic reading of unknown words (phonological recoding)
Sight reading
Structural and semantic (contextual) analysis
Writing Skills (including spelling, sentence structure)
Comprehension Skills
Individual Considerations
Font size and style
Fatigue
Distractibility
Perceptual difficulties
Learning problems
Other pertinent information from teachers, physician, related service, psychologist

TABLE 3.
SSPI Literacy Profiles for Three Students

Mary	Nancy	Ned
Communicating Responses		
Nods yes/no	Says yes/no (impulsive)	Yes/no switches
Finger points 3 second delay	Finger points 10–14 sec. delay	Toe points with 3 sec delay
Large movement gestures	Array of 4 choices	Array of 2–4 choices
Array 4 to 6 choice	Liberator-skilled	Macaw, Eyegaze
DynaVox2 (just learning it)		Computer with expanded keyboard
Physical Efficiency Areas		
Best positioning-wheelchair	Best positioning-wheelchair	Best positioning-wheelchair
Fair range of motion	Restricted range of motion	Left of midline, mounted slightly above left foot
Can point to words in sentences if words large, doubled spaced	Items to left, slanted, to point	Can point to words in sentence, and selects words out of an array of 3 words
Can motorically point well to an array of 4 words	Items to left, 12 inches from face	
	Can not point well to words	
Literacy Functioning Areas		
Knows book orientation	Lacks book orientation	Knows book orientation
Tracks across page	Unsure how to track across page	Can track across sentence
Identifies consonants and vowels 85% accuracy	Identify consonant & vowels 90% accuracy	Identifies all consonants and some vowel sounds

TABLE 3.
Continued

Mary	Nancy	Ned
No consonant blends, digraphs diphthongs, vowel digraphs, or or prefixes or suffixes	No consonant blends, digraphs, diphthongs, vowel digraphs, or prefixes or suffixes	Knows few consonant blends digraphs, but no diphthongs vowel digraphs, prefix or suffixes
Identifies some sight words	Identifies some sight words	Knows 10 to 20 sight words
Cannot phonetically decode	Cannot phonetically decode	Cannot phonetically decode
Knows sentence structure	Not know sent. structure	Not know sent. structure
Reading Recognition: K.8*	Word Identification = 1.75**	Word Identification = 1.25**
Reading Comprehension: K.0	Passage Comprehension = K.75	Passage Comprehension = K.0
Individual Considerations		
30–45 point font to allow for accurate point	30 point font	48–72 point font due to materials placed at foot
Distractibility	Unfamiliar Times New Roman font	Distractibility
	Fatigues after 30–45 minutes	
	Impulsive responding	

*PIAT (for both recognition and comprehension)
**Woodcock Reading (for identification and comprehension)

Nancy's SSPI Literacy Profile shows that she had strong AAC skills (using her Liberator) and could point to an answer given a four word array. Although she had a verbal yes/no, she sometimes answered impulsively without fully looking at the material (word) presented to her. However, her pointing was often slow, with 10 to 14 second delays. She could confirm accuracy by saying "yes" or "no" after pointing to a choice. She was able to use her Liberator to spell, as well as a computer when accessed through the Liberator. She had over 250 programmed words/phrases. Her vocabulary was sufficient for asking questions regarding reading. Her device was used for writing, but was not used for reading. Due to her visual impairment, she was unable to see the visual display of what she had selected. Nancy received reading instruction with a number of different reading approaches since she entered school. Most of these approaches had a phonetic base. Several years ago a Rebus symbol approach to reading was attempted, and the last few years she has been taught using the Edmark program. She was unfamiliar with the "a" and some other letters in Times New Roman font. In addition, she appeared to initially have some difficulty visually discriminating c–a and b–d–p–q, and auditorally discriminating m–n. She demonstrated strong spelling skills and was tested to be at a 5th grade spelling level if allowed phonetic spelling; otherwise a second grade level on the Wide Range Achievement Test (WRAT 3). However, when asked to make a sentence, she used the phrases on the Liberator and had difficulty with the semantic structure. She was assessed as being on a 1.4 grade equivalent for reading recognition. She showed significant fatigue after about 30 minutes of instruction.

Ned's SSPI Literacy Profile indicates that his best means of response was a yes/no with his switches at each shoulder. He was able to point accurately with his left big toe and did not evidence fatigue accessing his device. However, during the winter months he showed significantly less energy due to his asthma. He had five pages with 32 symbols each on his Macaw which he knew well, and his teacher stated he needed more symbols. He constantly used his Macaw and started using a computer with an expanded keyboard (IntelliKeys) for spelling at the beginning of the study. Ned received instruction on Edmark and Houghten Mifflin last school year and was close to being on grade level (kindergarten) in reading. His teachers were concerned that he would fall behind in reading due to the severity of his physical disability and lack of verbal output. He knew 10 to 20 sight words; he could not read a simple sentence. He was assessed as being on grade level at the end of kindergarten last year.

ASSISTIVE TECHNOLOGY AND ADAPTATIONS

Based upon the results of the SSPI Literacy Profile, the teacher needed to closely examine possible assistive technology devices and material adaptations that would be needed to teach reading to each student. The areas addressed were communication responses, physical efficiency areas, literacy functioning areas, and individual considerations. As seen in Table 4, all reliable communication responses were selected for each student. Optimal student and material positioning were determined, including the need for materials being elevated, slanted, or placed on one side to accommodate range of motion restrictions and field of vision. Use of slant boards, clamps, or dycem (thin plastic material which holds items in place) for stabilization was individually determined. Print needs were adapted based upon visual impairment (Nancy), the need for larger targets for pointing (Mary), or the need to see material when positioned at his foot (Ned).

While diagnostic distractor arrays and error analysis were adaptations in the Nonverbal Reading Approach that allowed assessment of whether the student was reading the word correctly, alterations were also needed to assess comprehension and writing. Comprehension adaptations included using a distractor array of pictures, using the AAC devices with words or pictures, specific questioning of definitions, and the computer with words or pictures. Writing and spelling adaptations included arranging words into sentences, using AAC devices or the computer to spell or write. The ability to review words that were taught included the use of card readers as well as homework with an AAC device or computer review with auditory feedback.

Depending upon the SSPI Literacy Profile and progress of the student, several additional activities were performed. These activities included spelling with their augmentative communication devices, using Boardmaker (See Appendix) to make pictures for comprehension, arranging words into sentences, and making stories out of the learned words to practice reading skills. Comprehension was also reinforced through questioning the student regarding meanings of words and sentences. The technique of filling in the blank with the appropriate parts of sentences was also used. In some instances, the student played "teacher" asking the teacher to sound out the word (by saying each letter sound and combining into a word). The teacher sometimes made mistakes and the student needed to identify these errors.

PROCEDURE

Curriculum and Activities. The Nonverbal Reading Approach was used to teach Direct Instruction (DI) reading programs. Two DI reading programs were available: Reading Mastery and Corrective Reading. The Reading

TABLE 4.
Literacy Adaptations and Technology

SSPI Literacy Profile	Possible Adaptations/Technology
Communication Responses:	
a) To Teacher Instruction	Finger point, yes/no gesture, DynaVox2 (Mary) Slow finger point, yes/no verbal, Liberator (Nancy) Toe point, yes/no switches, Macaw (Ned)
b) Spelling/Writing	AAC device, computer (expanded keyboard for Ned)
Physical Efficiency Areas:	Instruction in wheelchair due to best positioning (all) Midline, slant board, dycem (Mary) Left side, elevated (Nancy) Left side of foot, slanted, clamps (Ned) Four item array (Mary & Nancy), three item for Ned
Literacy Functioning:	*Type of Literacy:* Conventional Literacy *Literacy Approach:* Direct Instruction *Instructional Modification:* Nonverbal Reading Approach *Comprehension Adaptations:* Distractor Array of pictures using Boardmaker Literacy page with pictures of meanings on AAC Computer choices of words (IntelliKeys, Hyperstudio)

TABLE 4.
Literacy Adaptations and Technology

SSPI Literacy Profile	Possible Adaptations/Technology
	Writing/Spelling
	Words make sentences on cards and AAC device
	Spell and compose with AAC or computer
	Reading/Writing Review
	Modified homework (word cards, stories)
	Card Readers (sounds, words, sentences, story)
	Computer with auditory feedback (Write Outloud)
	Words/ Pictures on AAC device for practice
Individual Considerations:	Distractibility- change locations, face toward wall (Mary, Ned)
	Fatigue after 30 minutes, take breaks, teach in a.m. (Nancy)
	Health factors (Nancy, Ned)
	Enlarged print (Mary, Nancy, Ned)

Mastery programs are designed for students in grades one through six, while the Corrective Reading programs are designed for anyone from middle school through adulthood who is not a competent reader. Both programs provide explicit systematic instruction in phonics to students who have not learned letter sound relationships and blending skills. When learning individual words, the student, is cued to, "Sound it out" or ("Sound out the word"). The teacher points to each letter while the student says each sound without pausing between sounds (e.g., iiiiissss). Upon correctly sounding it out, the student is cued, "Say it fast" in which the teacher points to the word and students verbalizes the word (e.g., is). This strong emphasis on phonics is combined with instruction in comprehension, following instructions, and remembering what is verbalized. Learning how to read is followed by instruction and practice in reading to learn.

The effectiveness of these programs has been demonstrated with children who have reading difficulties and those from disadvantaged backgrounds, as well as children in general education and special education (Adams & Engelmann, 1996; Becker, 1977; Carnine, Silbert, & Kaneenui, 1977; Gersten, Carnine & Woodward, 1987; Polloway, Epstein, Polloway, Patton, & Ball, 1986). While there is extensive evidence of the effectiveness of DI reading programs for teaching students in general and special education, no one has adapted these reading programs for students who have severe speech and physical impairments. Mary and Nancy were assessed and placed in the Corrective Reading Program, while Ned was placed in the Reading Mastery Program.

Nonverbal Reading Approach. Upon examining each student's profile (Table 3) and necessary individualized adaptations (Table 4), the Nonverbal Reading Approach was selected to be used and adapted to the Direct Instruction curriculum. All three SSPI Literacy Profiles showed that the students did not always look at the entire word, and it was uncertain where the student was looking due to their motoric and communication constraints. Because of this, each student would initially begin by being taught to sound out each letter and then blend them together. (See Table 5).

When first learning a word, the instructor showed the word then pointed to each letter or used a card to move along the word showing which letter was being sounded out. The student was instructed to say the sound "in your head" while the teacher said the sound aloud. Then the student was to say the sound outloud. Saying the sound outloud was to assure active participation for Mary and Ned. For Nancy, saying the sound outloud helped assess if she identified the correct letter, since some of her sounds approximated letter sounds. The student was then instructed to "sound out the word in your

TABLE 5.
Use of Nonverbal Reading Approach with Direct Instruction

Process	Example Script
	1. T: “I'm going to give you some words to read. First, you will sound out the word, then I'll give you some spoken (or written) choices and you tell me which is correct. OK? Here we go.”
	2. T: “Look at this word.” (T. shows student entire word.)
Internal speech	3. T: Teacher shows only the first letter of the word (by covering other letters with a card) and says, “Say in your head the first sound.” *(If introducing a word, T. says the sound outloud as S. uses internal speech.)*
Active participation	4. T: “Now, say the sound out loud.”
	S: Says sound approximation (or anything, if possible).
	5. T: Shows the next letter of the word by moving a card and repeats steps 3 through 4 for the entire word.
Internal speech	6. T: “Now, in your head, sound out the word. Don't stop between sounds.” (T. - Point to each sound) *(If introducing a word, T. slowly sounds out the word outloud as S. sounds out word using internal speech).*
	7. T: ‘Now, say it in your head fast.” *(If introducing a word, T. says the word out loud. Teacher does not continue with the rest of the steps, but goes on to introducing the next word).*
Choices/ Diagnostic Distractor Array	8. T: “I'll give you four choices. Your choices are: [choice 1], [choice 2], [choice 3], [choice 4]. Is it [choice 1]? (wait for S. response). Is it [choice 2]?, etc.).” (T. points to the choices.)
	S: Student indicates his/her answer.
	9. T: If student gives correct answer, confirm correct selection. If student gives incorrect answer, reteach.
Data	10. Record answer on data sheet.
Error Analysis	11. Analyze errors.

head without stopping between sounds" as the teacher verbally blended the sounds together. Lastly, the student was instructed to "say the word in your head fast."

When initially being assessed on a word, the instructor showed the word and pointed to each letter (or used a card) as before. The same procedure was followed when first introducing a word, except that the instructor did not say the sounds or word aloud. The student was then given 3 or 4 written or oral choices from which to choose the correct response. The diagnostic distractor array was carefully selected to provide possible alternatives that were close in pronunciation or visual display to the correct word to determine if the student really knew the word.

Student errors were carefully documented and an error analysis was performed to determine any patterns of the types of errors the students were making. Identified errors resulted in adaptations or repeated practice, depending upon the type of error. Diagnostic distractor arrays were designed to include the errors that the students were making. For example, if a student confused "m" and "n" sounds, after teaching the concept or adapting for it, the diagnostic distractor arrays included distractor words that contained the error the student was confusing with the correct word to assess if the student had learned the correct response.

DESIGN AND RELIABILITY

Due to the individualized nature of teaching reading to this population, this pilot study primarily used a case study format. The dependent variables for all three students were the percentage of words mastered. Additional dependent variables for Nancy and Ned were word attack, word identification, and passage comprehension as measured by the Woodcock Reading Mastery Tests-Revised, and for Mary, reading recognition and reading comprehension as measured by the PIAT. The independent variable was the Nonverbal Reading Approach with Direct Instruction. Because there was no control group with which to compare the participants' progress, their rate of reading gain prior to the study (i.e., current reading level over the number of years instructed in reading) was compared to their rate of reading during implementation of the reading over one academic year (Snyder-McLean, 1987). That is, participants served as their own controls. A Reversal Design (Barlow & Hersen, 1984) was used to determine the effect of the selection from using diagnostic distractor arrays. Reliability checks occurred for a minimum of 25% of the total number of sessions for each student. Interobserver agreement was calculated by dividing the number of agreements of occurrence of the target behavior by the total number of agreements and disagreements and then multiplying by 100. The interobserver agreement checks resulted in 100% agreements.

RESULTS

Each of the three students showed progress in reading using the Nonverbal Reading Approach with the Direct Instructional programs. Mary completed 43 out of 65 lessons before the end of the school year. Nancy completed only 29 of the 65 lessons due to frequent illness from Thanksgiving until the end of March. Ned, who was in the Reading Mastery Program, completed 66 lessons out of 160 in the first grade level. (See Table 6.) Unlike the other two students who had reading lessons approximately four days a week, he received DI reading lessons using the Nonverbal Reading Approach one to five days a week, depending upon his asthma. Overall, he averaged two to three days of instruction with DI reading lessons using the Nonverbal Reading Approach. However, he was also participating in the whole language reading approach with his first grade class. Having difficulty with this system, he primarily received instruction in story comprehension with his first grade class.

CASE A (MARY)

Mary was introduced to 296 words in the reading program and was able to correctly identify 261 (88%) by the end of the school year. At the beginning of the program, she could not consistently identify consonant blends (e.g., br, pr, st), consonant digraphs (e.g., ch, sh, th), or diphthong sounds (e.g., ow, oi, oy, ou). She did not demonstrate the ability to phonetically identify common suffixes or prefixes or to blend phonemes into words. At the end of the year, she could phonetically identify targeted consonant blends, consonant digraphs, and diphthongs. She could also identify common suffixes and blend phonemes into words. At the beginning of the program, she was primarily identifying individual words, but at the end of the program she could read short stories with words she had learned with 95% comprehension.

An analysis of Mary's errors suggested the need for antecedent prompts and adaptations that were successfully faded (gradually removed) before the end of the school year. When her error analysis showed reversals (ma/am) a red dot was placed under the beginning letter to help her learn where to start reading. After about two months, the red dot was completely faded. Since it was difficult to tell if she was attending to the letter that she was sounding out with internal speech, a small card was used to move along the word, displaying the letter being sounded out. Over time, Mary independently took

TABLE 6.
Results of Case Study

	Student 1 "Mary"	Student 2 "Nancy"	Student 3 "Ned"
Lessons Completed	43 (out of 65)	29 (out of 65)	66 (out of 160)
Number of Words Mastered	261	92	85
Percentage of Words Mastered	88%	58%	88%
Spelling Accuracy	70%	85%	80%–100%
Post test* Reading Recognition or Word Identification	1.5 grade	2.0 grade	2.25 grade
Word Attack	——	1.2 grade	2.0 grade
Post test Passage/Word Comprehension	1.5 grade	1.2 grade	1.75 grade
Reading recognition gain (or word identification)	7 months gain	2.5 months gain	1.0 year gain
Comprehension gain	1.5 years gain	4.5 months gain	1.75 year gain

* Post test results for Mary were from the PIAT
Post test results for Nancy and Ned were from the Woodcock Reading Mastery Tests

the card and moved it along the word as she quietly looked at the letter (telling the teacher she was "saying it in her head"), then she made a noise to say it aloud. Over time, when she was presented with a word, she was asked if she knew what the word was or if she needed to sound it out. For over half of her words, she demonstrated automaticity by quickly identifying the word and not needing to phonetically decode the word or use a card. This process of automaticity occurs as the reader becomes skilled and shifts from the simple one-to-one correspondence of sound and letter to being able to recognize the word as a whole (Share, 1995).

The error analysis also showed that Mary had difficulty learning some of the short vowel sounds and knowing whether to use the long or short sound. She was given a short vowel sheet with a picture of a familiar item for each short sound (e.g., "a" with an apple picture). When sounding out a word, she first identified it as a long vowel sound or a short vowel sound based on the CVC (consonant-vowel-consonant) rule or "e"rule. If she was unsure, she sounded it out both ways, using the short vowel sheet to help her with the short vowel sounds.

Some independent reading practice of words encouraged maintenance of skills. Besides AAC and computer activities, Mary especially liked to use the Card Reader. She first read the word or phrase, then she placed the card into the slot and tapped it so it would run through the reader, reading aloud the word or phrase to check herself She also ordered the cards into sentences. Mary and her mother liked this activity so much that they planned to purchase one.

Mary had a strong listening receptive vocabulary and was able to demonstrate comprehension of most words once she was able to sound them out. She matched pictures to the words or pointed to the correct word when given a definition or shown the meaning of the word. (For example, when shown a fist, she pointed to the word fist. When asked which word pertained to money, she pointed to the word, "cash"). Her comprehension was assessed by matching what was said to symbols placed on her AAC device. For example, given the written sentence, "She is petting the sheep and singing," she read the sentence using internal speech, then selected the appropriate symbols (out of an array of 35) which were "she," "is," "pet," "ing," "the," "sheep," "and," "sing," "ing." She was able to quickly master the symbols and had a high rate of accuracy when reading the sentence and pointing to the symbols.

Mary's lack of comprehension for some words was attributed to inexperience due to her physical impairment, which, for example, never put her in contact with an ant, sled, mast, trotting, or mending. Although spelling was not targeted in this study, spelling was taught along with this reading program. Her teacher and mother found her spelling skills significantly increased. On spot checking, her spelling accuracy was at 70%, however there is no baseline measure for comparison.

Reading recognition and reading comprehension were assessed as pre- and post- measures, one year apart using the PIAT. Although most of the test is in a multiple choice format, items that required oral reading were adapted with a four word array. Mary's pretest scores were K.8 grade equivalent in reading recognition and K.0 grade equivalent in reading comprehension. At the end of the academic year using the Nonverbal Reading Approach with Direct Instruction, her reading recognition and reading comprehension were both 1.5 grade equivalent. In one school year she made seven months academic gain in reading recognition and one and a half years academic gain in reading comprehension, compared to the previous 11 years of school during which she made only eight months gain in reading recognition and no gains in reading comprehension. While there was no pretest spelling assessment, at posttest Mary demonstrated a 1.1 grade equivalent in spelling.

CASE B (NANCY)

Nancy was introduced to 158 words and was able to identify 92 words by the end of the year (58%). At the beginning of the program, she could not identify consonant blends, consonant digraphs, diphthong sounds, or vowel digraphs. She did not demonstrate the ability to phonetically identify common suffixes or prefixes or blend phonemes into words. At the end of the year, she could phonetically identify targeted consonant blends and consonant digraphs. She could also identify common suffixes and blend phonemes into words. At the beginning of the program she was unable to discriminate between the top and the bottom of the page, and she did not know where to begin to read on a page.

Error analysis showed that Nancy also reversed some letters. Like Mary, the red dot was used as an antecedent prompt to assist her in identifying where to start. This was successfully faded over time. She also showed a tendency to flip letters (cast/cats), not attend to the entire word when blending it together (dim/did, seem/see), and occasionally not attend to the first letter (sing/ring, cod/odd). These errors were addressed by highlighting letters (using a white board with different colors or sizes of targeted letters and underlining parts of the word), reinforcing the left to right progression of sounding out a word, and repeating words correctly when an error was made. Since Nancy was a strong speller, she was encouraged to spell out the word first on her AAC device, then sound it out when she read it. While these strategies were somewhat effective, her illnesses from Thanksgiving to the end of March affected her accuracy rate; some days it was as low as 20% for a lesson. Even when given the option to identify the word without sounding it out, Nancy elected to sound out the word first. Little automaticity was observed.

Similar to Mary, Nancy had a strong listening receptive vocabulary and was able to demonstrate comprehension on most words, once she was able to sound them out. She matched some pictures to the words or pointed to the correct word when given a definition. Lack of comprehension for some words was attributed to inexperience due to her physical impairment. Although spelling was not targeted in this study, spelling was taught along with this reading program. On spot checking, her spelling accuracy was at 85%, although there is no baseline for comparison.

Pre- and post-test administrations of the Woodcock Reading Mastery Test-Revised were administered one year apart. Much of the test was adapted to a multiple choice format for Nancy. Although this alteration changes the validity of the test, and tends to inflate the scores, her progress can be compared between the two administrations using this same adaptation. Her pretest scores were 1.75 grade equivalent in word identification, K.75 in word attack and K.75 in passage comprehension. By the end of the school year during which she used the Nonverbal Reading Approach with Direct Instruction, she scored 2.0 grade level in word identification and 1.2 in both word attack and passage comprehension. In one academic year she made a two and a half months academic gain in word identification, as well as four and a half months academic gain in both word attack and reading comprehension. During her previous 16 years in school, Nancy averaged a little more than a month gain in word identification (1.1) and less than half a month (.47) gain in word attack and passage comprehension for each year.

CASE C (NED)

Ned was introduced to 96 words through the reading program and at the end of the year demonstrated word recognition of 85 of them (88%). Ned progressed from reading individual words to reading short sentences. At the beginning of the program, he did not show decoding skills, but by the middle of the year he began sounding out the words independently, using internal speech with new and familiar words. (For example, when first presented with the word "if" he sounded it out with internal speech and correctly selected the word from a spoken diagnostic distractor array.)

Error analysis showed that Ned had difficulty with vowel sounds (neat/not, fat/fit). This may have been due to distractibility and the inattention to details. He often self corrected when the vowel was pointed out and he was asked to "say it in his head" then sound out the word. Further prompting was not needed, since the Reading Mastery program already provides different symbols for each long vowel (a line over the vowel) and has silent letters in a small font. Further practice of vowel sounds was provided to Ned with improvement of correct letter sound identification.

Comprehension activities entailed primarily picture symbols and some oral questioning. In word comprehension, Ned read the word using internal speech and selected the correct picture (made from Boardmaker) representing the word meaning. He had a high accuracy rate, except the few times he misinterpreted the picture, such as when given the word "sack," he identified the picture as a bag and was unable to make a match. Passage comprehension contained an array of pictures. For example, the passage, "He is an ant. He has a sock on his feet." was presented and Ned read the passage using internal speech. He was then asked a comprehension question, "Who is this about?" He answered by pointing to a boy or girl. He was then asked, "Which word told you it was a boy?" Ned would point to the word "he." He was asked who he was and Ned had to select from a picture array of "boy," "cat," "ant." When asked, what is this word (pointing to "sock"), he selected the correct word from pictures of "sock," "sack," and "cap." He was also given a picture array of "feet," "hand," and "head" to select the correct picture. He did this with a high rate of accuracy. However, like Mary and Nancy, because of his physical impairment, he was unfamiliar with many common words and demonstrated a lack of exposure and life experiences (e.g., football, mitt). This required teaching with the actual object.

Comprehension was assessed by Ned reading a passage and pointing to words to answer. For example, "Which word can you eat? (ham), Which word rhymes with cat? (sat)." He often answered with 100% accuracy. Although spelling was not targeted in this study, spelling was taught along with this reading program as well as in his regular class. He spelled using the letter page on his AAC device or alternate keyboard (IntelliKeys) which displayed the alphabet and was connected to his computer. He spelled with 80 to 100% accuracy on his first grade spelling tests. His success with spelling was attributed to the Nonverbal Reading Approach by his regular and special education teachers.

Pretest and posttests were given using the Woodcock Reading Mastery Test-Revised. As with Nancy, the test was adapted into a multiple choice format to allow him to respond. The pretest showed word identification at grade 1.25, word attack at 1.25, and passage comprehension at K.0. The posttest showed word identification at grade 2.25, word attack at 2.0, and passage comprehension at 1.75. These grade equivalent scores were thought to be somewhat inflated due to the ease of some of the multiple choice words. However, using the same format for both pre- and post-testing, Ned demonstrated a full year academic gain in word identification, three-quarters of a year's gain in word attack skills, and a year and three-quarters gain in passage comprehension. These improvements are consistent with improved reading over the year in his academic work.

As previously noted, Ned also received reading instruction in the regular first grade class. However, the first grade teacher, who used a whole language reading approach, found Ned unable to participate in the reading lessons or to read along with the first grade class using the whole language approach. This teacher felt that Ned was benefiting from the Direct Instruction program with the Nonverbal Reading Approach and recommended, as did the special education teacher, that Ned receive instruction in an alternative reading program (Direct Instruction with the Nonverbal Reading Approach) next year. All other classes in general education would remain the same.

A reversal design was implemented to determine if the type of distractor affected the students' responses. Mary and Nancy participated in the reversal designs. (See Figure 1). In the baseline condition ("A"), unknown words were introduced in commonly used nondiagnostic distractor arrays in which the words were grossly dissimilar with only initial consonants being different (e.g., target word "rat" and distractor array "mat," "hat," and, "cat"). Both Mary and Nancy showed high accuracy rates. In Condition "B," the same targeted words were presented in diagnostic distractor arrays with only the vowels or the final consonant being different (e.g., target word "rat" and diagnostic distractor array "rat," "rid," "reed," and "ram"). Both Mary and Nancy showed low accuracy rates. When reversed back to condition A, a high accuracy rate was obtained and when diagnostic distractor arrays were repeated, similar finding occurred.

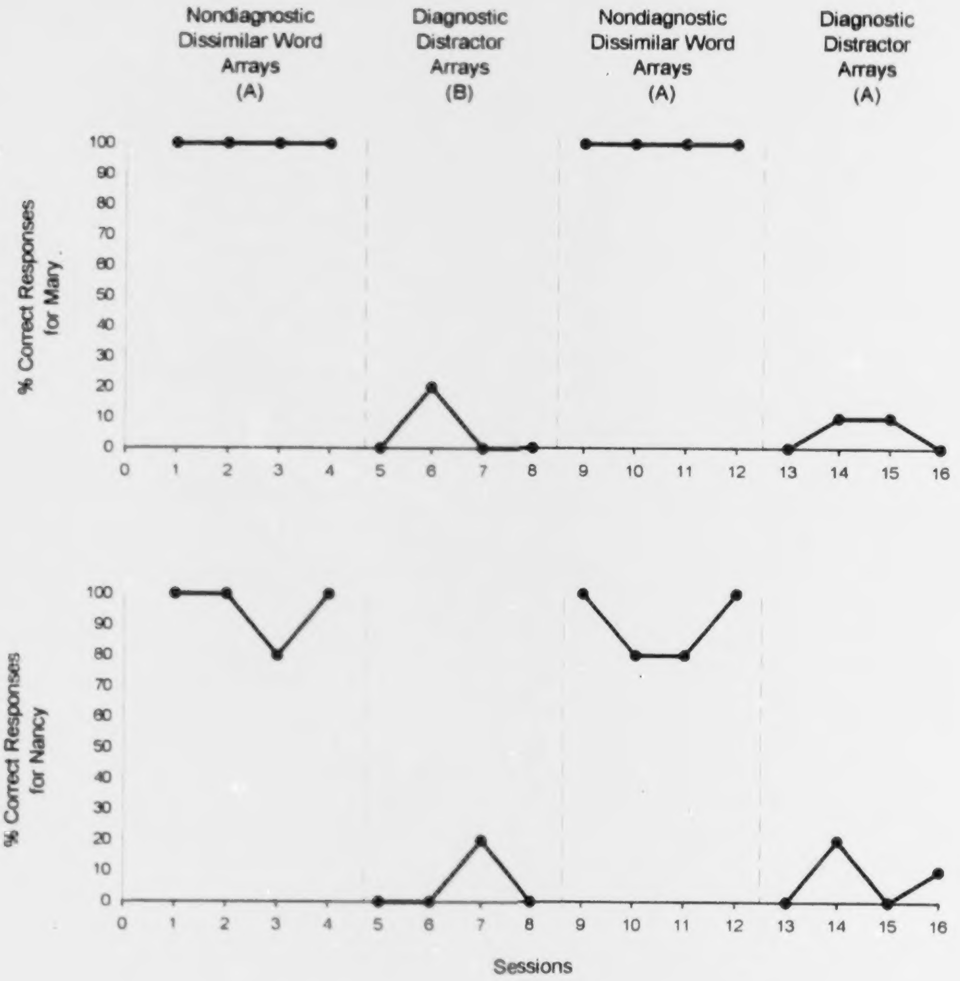
DISCUSSION

Data indicated that all three students made progress using the Nonverbal Reading Approach with Direct Instruction reading programs. This was demonstrated by gains in skills across the school year in reading, and the gains indicated on the pre-post test results. Teachers and parents expressed satisfaction with this reading approach and the gains made.

Mary made the most dramatic progress, going from reading single words to reading paragraphs with automaticity. Her gains on the PIAT were also impressive, considering she had made kindergarten level gains for the 11 years she had been in school, and then in one year made almost a year gain

Figure 1

Reversal design showing effect of diagnostic distractor arrays.



in reading. Mary began the study with the most book knowledge and skill in sentence structure. This is attributed to her interest in reading and regularly being read to at home. Also, at 16 years of age, she had a great deal of exposure to spoken language and its structure. Mary also had the most motor capability. Although her cerebral palsy is severe, she can awkwardly and slowly follow along a sentence by pointing, turn the pages of an adapted book, and manipulate a reading card. These skills allowed her more independent practice at home and may have contributed to her progress.

Nancy showed the least gains of the three students. However, considering she was ill 44% of the academic year, her gains were satisfactory. She began the study with spelling skills that were quite high (5th grade) compared to her reading skills (kindergarten and first grade). One strategy used in the study was to use her strength in spelling to assist her with reading, by having her spell the targeted word and then practice blending the word using internal speech. This technique was found to be helpful and reinforces the importance of building on a person's strengths when possible.

Nancy was the strongest AAC user of the three students, using Minspeak on a Liberator. Minspeak uses a combination of icons to make different messages. It was felt that her AAC device and its use was well designed for assisting her in verbal communication, but not for promoting reading literacy. One problem is that the construction of messages on her AAC device does not follow regular sentence construction, which could contribute to her lack of knowledge about constructing sentences. Also, she does not see words but icons when she constructs her messages. This reduces her exposure to print. Nancy primarily relies on her knowledge of the position of the letters of the alphabet, rather than seeing the letters to spell out words. Being unable to see the written display of what she has spelled out further reduces her exposure to print. Her AAC device must be connected to a computer with enlarged print so that she can see what she has written. Due to the type of AAC system she uses, it was not possible for Nancy's system to promote reading as was done with Mary. Similarly, Ned's AAC device was not set up for proper construction of sentences or the vocabulary to use proper sentence construction. Although this set-up is desirable for quick and efficient communication, it does not promote literacy skills. While selection of AAC and its vocabulary construction should primarily take into account communication factors, its use for reading and writing literacy skills should also be considered.

Although modifications were made in Ned's general education class for reading, he made poor progress in the reading activities in the class. In contrast, he made good progress using Direct Instruction and the Nonverbal Reading Approach. During the time that the Direct Instruction Reading Program with the Nonverbal Reading Approach was being taught, Ned made dramatic gains in his ability to communicate by typing words. He began typing short sentences on the computer and was able to phonetically spell untaught words so another person could understand what he was trying to say (e.g., jkusi = jacuzzi). It is strongly felt by all his teachers that this increased ability to communicate through spelling words and sentences will greatly enhance his reading performance in the future.

Pictures were used to assess comprehension of the word meanings. Although the students benefited from their use, there are several cautions regarding their use. First, picture use would not be a good strategy if it requires the student to learn both the written English code and an abstract symbol code. In this study, Nancy was able to very quickly learn the symbols and use them for assessing word comprehension. She was able to use abstract pictures, including separate word ending (e.g., ing) to match to each word contained in various written sentences. However, this technique would be inappropriate if it took a long period of time to teach the abstract symbols. A second caution is that students may not know the meaning of pictures, even if they resemble their referent (e.g., most Boardmaker symbols). For example, errors can still occur in the identification of the symbol, such as when Ned could not identify the picture of a sack for the word "sack" because he thought it was a picture of a bag. Care must be taken that the student knows the picture in order to match it with the word. A third caution is that picture comprehension tasks cannot take the place of written or spoken diagnostic distractor arrays, since comprehension and decoding are different skills. Teaching a student to decode a word, regardless of its meaning, is a critical skill for literacy. Picture matching does not necessarily assure that proper decoding skills are in place. If the picture distractors are chosen as carefully as decoding distractors, they should indicate that the student is able to decode the word when the student chooses the correct picture. However, if the student chooses the incorrect picture, the teacher does not know if it is because the student decoded incorrectly, did not comprehend what he/she decoded, or was not familiar with the picture options.

The reversal design supported the need for careful selection of the distractor arrays. A more precise evaluation of the student's ability was found through using a diagnostic distractor array, rather than a nondiscriminatory one. The diagnostic distractor array demonstrated that the students had not really leamed the words, while the nondiscriminatory array resulted in useless data, indicating that the words were learned. An error analysis of the selection of the words from the diagnostic distractor arrays were also able to indicate the types of selection errors that were made and allowed the teacher to provide further instruction in these areas. (Later in the year, these words were mastered using diagnostic distractor arrays.) With the student's inability to speak, the teacher cannot hear how the student is reading words; therefore, a diagnostic distractor array needs to be carefully constructed to include previous and potential errors. Further research is needed to determine the effect of different types of distractor arrays and their impact on learning.

Although the data on these three students using Direct Instruction with the Nonverbal Reading Approach to promote reading are encouraging, further research is needed in this area. A greater number of students is needed, as well as students with different reading ability and experience to help determine the effectiveness of this approach in the field of physical/health disabilities.

In summary, three students received instruction during an academic year using Direct Instruction and the Nonverbal Reading Approach. The data indicate that the Nonverbal Reading Approach's use of internal speech, diagnostic distractor arrays, error analysis, and assistive technology resulted in significant reading gains. Gains were of such magnitude that parents reported finding appreciable improvement in their childs' reading ability at home. As Mary's mother so aptly wrote: "I can't tell you how happy I am with this [reading] program. This really is teaching 'Mary' to read. 'Mary' has always been able to memorize words, but no one knew how to teach her to read! This is just wonderful."

APPENDIX

Boardmaker—	Boardmaker is a software program that holds thousands of symbols from the Picture Communication Symbols. Overlays and educational material may be made with the symbols. The program includes a built-in drawing program to customize the symbols.
DynaVox2—	DynaVox2 (Dynamic Voice Output Communication Aid) is an electronic AAC device with changeable touch screen displays (dynamic display). The screen displays symbols which can represent one word, phrase, or serve as a category symbol. When touching a category symbol, the screen changes to display an entirely different category of symbols. This device has a high-quality synthesized speech output, as well as a print display.
IntelliKeys—	IntelliKeys is a touch sensitive alternate computer keyboard. Overlays can include the alphabet, numbers, arrows, basic writing, and custom overlays.
Liberator—	The Liberator is an electronic communication device that uses Minspeak, which is a system of icon combinations that represent words, sentences, or phrases. Symbols can be

	selected by touching the icons on the Liberator's keyboard. It comes with print and speech output.
Macaw—	The Macaw is an AAC devices that uses digital recording and playback. It can be accessed by either direct selection, or switches for auditory or visual scanning. It is a less complex AAC system than the DynaVox and Liberator, and holds less vocabulary.

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VERMONT'S GUIDELINES FOR RELATED SERVICES: SUPPORTING THE EDUCATION OF STUDENTS WITH DISABILITIES

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ABSTRACT

Related services (e.g., speech-language pathology, occupational therapy, physical therapy, audiology, psychological services) are a vital aspect of appropriate educational support for some students who have disabilities. This article describes Vermont's Guidelines for Related Services *and the process by which the document was developed. The article describes the activities of a grassroots group of consumers, providers, program and agency personnel, and advocates called the* Related Services Work Group, *to initiate a statewide dialogue on related services for students with disabilities in inclusive schools. Implications for how this information can be used in school improvement planning are discussed.*

The Individuals with Disabilities Education Act Amendments of 1997 (IDEA) state:

> The term "related services" means transportation, and such developmental, corrective and other supportive services (including speech-language pathology and audiology services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, social

> work services, counseling services, including rehabilitation counseling, orientation and mobility services, and medical services (except that such medical services shall be for diagnostic and evaluation purposes only) as may be required to assist a child with a disability to benefit from special education, and includes the early identification and assessment of disabling conditions in children. 20 U.S.C. § 1401 (22).

This article describes *Vermont's Guidelines for Related Services*. These *Guidelines* are consistent with the IDEA definition of related services, and include promising and exemplary practices used in inclusive schools (England, 1994; Giangreco, 1996; Giangreco, Edelman & Dennis, 1991; Giangreco, Edelman, Luiselli & MacFarland, 1996, 1998; Giangreco, Edelman, MacFarland & Luiselli, 1997; McEwen, 1995; McWilliam, 1996; Orelove & Sobsey, 1996; Rainforth, 1991; Rainforth & York-Barr, 1997; Thousand & Villa, 1992; York, Giangreco, Vandercook, & Macdonald; 1992). Additionally, the article describes the process by which the guidelines were developed, including: (a) identification of stakeholders; (b) activities and timelines; (c) public response and input; (d) selecting priorities; and (e) action planning and dissemination.

Vermont's Guidelines for Related Services (see Tables 1–5) are composed of 60 statements divided into five topical areas. Each area addresses an important aspect of related services. The five topical areas are:

1. Access to Knowledge and Information
2. Roles of Related Services Providers in Determining Eligibility for Special Education
3. Determination of Related Services
4. Implementation of Related Services
5. Evaluation of Related Services

The development of *Vermont's Guidelines for Related Services* was intended to: (a) highlight the importance and value of related services for students who require such supports; (b) encourage conversations among stakeholders (e.g., family members, professionals, advocates, community members) about a variety of related services issues; (c) serve as a starting point for educational teams to develop a shared understanding of exemplary and promising practices; and (d) assist teams in using related services in ways that ensure that students with disabilities receive an appropriate public education.

TABLE 1.

A. Access to Knowledge and Information

Appropriate determination, implementation, and evaluation of individualized related services for students with disabilities necessitates that all team members (e.g., parents, teachers, special educators, administrators, related services personnel, paraprofessionals, LEA representatives) have access to information about and knowledge of:

A1. student characteristics, family priorities, and educational goals (e.g., hopes for the future, preferred learning styles, motivations, as well as their physical, cognitive, sensory, and emotional capabilities);

A2. the educational context in which the student is learning (e.g., preschool, general education classroom, community work site);

A3. the legal definitions and interpretations of "related services" based on law and regulations, administrative rulings, and court decisions about related services that interpret laws and regulations;

A4. the skills and activities associated with various related services disciplines (e.g., speech-language pathology, physical therapy, occupational therapy, psychology, orientation & mobility, social work, school health services);

A5. a common understanding of service delivery definitions (e.g., screening, evaluation, direct service, indirect service, consultation, monitoring);

A6. the variety of related services that are available regionally, statewide, and nationally;

A7. the professional background and current skills of the team members with whom they are working;

A8. the principles and procedures of collaborative teamwork;

A9. the shared beliefs and attitudes of team members that will help them to build a common framework necessary for effective team functioning; and

A10. processes for determining, implementing, and evaluating related services.

TABLE 2.
B. Roles of Related Service Providers in Determining Eligibility for Special Education

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Related services providers may be asked to work with, or as members of, evaluation and planning teams. The roles of related services providers in determining eligibility for special education include, but are not limited to:

B1. screening, observation of typical activities and environments, and/or interviews with the family and other team members to help identify students in need of more in-depth evaluation for special education;
B2. assisting the team in the development of evaluation questions for the evaluation plan;
B3. recommending appropriate assessment strategies to be included in the evaluation plan;
B4. coordinating with other service providers and the family in the development of an overall plan to ensure effective fact-finding and avoid duplication in assessment activities;
B5. conducting specialized assessment activities for which they are uniquely trained or qualified;
B6. interpreting and reporting on specialized assessment results with the team; and
B7. consulting with the family and school personnel to assist in making eligibility decisions.

DEVELOPMENT OF THE GUIDELINES

IDENTIFICATION OF STAKEHOLDERS

Spanning a period from the spring of 1997 through the fall of 1998, when the *Guidelines* were published in a brochure format by the Vermont Department of Education, between 150 and 200 Vermonters were involved in various ways in developing, editing, and finalizing these *Guidelines*. As with many grassroots efforts, this one began with a very small group of people. The group expanded to solicit input from many people, and then returned to a core group who conducted the bulk of the work: writing, editing, and distributing the final product.

In April 1997, the process was initiated by a special educator and two pediatricians, all of whom had experience with, interest in, and concerns about, a variety of related services issues. These three people called a local

TABLE 3.
C. Determination of Related Services

Determining individualized related services for students with disabilities should be:

C1. developed collaboratively by the family and educational staff with substantive input from related services providers;

C2. developed with the input of the student, when appropriate, to encourage self-advocacy, self-determination and relevance of services;

C3. considered and discussed using language that is readily understood by all team members, with minimal use of professional jargon;

C4. based on a single set of educational goals shared by the team and developed with consumer input (e.g., student, parents);

C5. developed after the student's educational program (e.g., annual goals, curriculum content, general supports) and educational placement have been determined to ensure educational relevance and necessity;

C6. educationally relevant so that services are directly related to the student's IEP (Individualized Education Program) and/or other documented educational curriculum (e.g., general education curriculum);

C7. educationally necessary, meaning that the absence of a service would interfere with the student having access to an appropriate education or participation in his/her educational program;

C8. selected judiciously by considering natural supports and employing specialists' supports that are *only as specialized as necessary;*

C9. provided during the school day if they are necessary for a student to benefit from special education, but schools are not required to provide services that may be appropriately administered other than during the school day;

C10. designed to avoid undesirable gaps, overlaps, and contradictions among service providers;

C11. reflective of a decision making process which leads to consensus if possible; or a decision by the Local Education Agency in cases where consensus is not achieved, subject to procedural safeguards; and

C12. documented specifically to include: (a) type (e.g., physical therapy); (b) relationship to the educational program (e.g., pertains to specific IEP goals); (c) mode of service (e.g., direct, indirect, consultation); (d) frequency and duration of service; (e) location of service provision; (f) initiation date; (g) evaluation date; (h) personnel; and (i) a plan of action for service provision.

TABLE 4.

D. Implementation of Related Services

Implementing individualized related services for students with disabilities requires that they:

D1. are consistent with the values underlying IDEA (e.g., individually appropriate learning outcomes; least restrictive environment provisions; participation with students who do not have disabilities);

D2. allow access to the same settings and activities available to students without disabilities;

D3. acknowledge the portability of services so that they may be offered in the most natural, inclusive, and least restrictive settings and ways;

D4. are not unduly stigmatizing;

D5. adhere to professional and ethical standards of practice;

D6. use exemplary practices that are supported by current literature and research;

D7. consider the privacy and dignity of the student and family;

D8. address the self-identified support needs (e.g., resource support, technical support, moral support, evaluation support) of students with disabilities, their parents, and their teachers;

D9. ensure that all appropriate individuals (e.g., teachers, special area teachers, related services providers, parents, instructional assistants) are informed about each student's related services;

D10. assist classroom teachers and staff in educating the student with disabilities within the context of the classroom in ways that contribute to, rather than disrupt, classroom routines and activities;

D11. allow roles and skills of related services providers to be shared with classroom staff as determined through consensus decision-making;

D12. ensure adequate training, support, and supervision for those implementing related services recommendations, including professional and paraprofessional staff, family members, and the student when appropriate; and

D13. deliberately plan for transitions, such as early childhood programs to school, between grades, and from school to adult life.

TABLE 5.

E. Evaluation of Related Services

Evaluating appropriately individualized related services for students with disabilities requires that:

E1. the related services pertain directly to the student's IEP and state educational standards so that team members know the proposed educational impact of the related services;

E2. the educational cycle includes an evaluation component as a vital and ongoing aspect of each student's educational plan;

E3. data about the impact of the services are collected, recorded, reviewed, and analyzed on a regular basis by the team, which includes the family (e.g., parents, guardian, student);

E4. data include a variety of relevant sources (e.g., direct observation by the related services provider, frequency counts, duration, percent of correct responding, teacher report, parent report, work samples, tests and quizzes, student projects and products, classmate feedback, self-evaluation methods by the student);

E5. student impact data are reported to parents and other team members on a schedule that coincides with typical school reporting periods and is reported in language that is readily understood, with a minimum of professional jargon;

E6. adjustments to the student's plan are made based on the analysis of data;

E7. adjustments made, and agreed upon, based on data collection are part of an ongoing feedback loop among all team members rather than an annual event; and

E8. the impact of related services is interpreted broadly to include progress on educational goals and access to educational settings and opportunities, as well as impact on valued life outcomes (e.g., health, safety, relationships, opportunities).

meeting, the purpose of which was to determine if there was sufficient interest to establish an "Agenda for Action" pertaining to related services issues for students with disabilities. Twenty-five individuals, representing a wide variety of professional disciplines and stakeholder groups, were invited to an initial meeting. Many represented more than one stakeholder group (see

Table 6). While a limited number of invitations were extended, anyone who wished to participate was welcome.

It was clear at the group's first meeting that the issues of related services were relevant statewide and that feedback from across the state was considered crucial. At this meeting the *Related Services Work Group (RSWG)* was formed as an ad hoc group for the purpose of addressing priorities pertaining to related services in our state. What began as a local/regional activity quickly became a statewide initiative.

The group completed two major tasks in 18 months, before becoming semi-dormant. The two tasks were: (1) development and statewide dissemination of the brochure *Vermont's Guidelines for Related Services;* and (2) development of a more complete manual titled *Related Services for Vermont's Students with Disabilities* (Dennis, Edelman, Giangreco, Rubin & Thoms, 1999). Plans were discussed to revive the group to conduct statewide training or focus forums on related service issues in the future.

To ensure statewide access to the discussions regarding related services, subsequent communications from the RSWG were sent to all initial participants as well as the Board of Governors of the *Vermont Coalition for Disability Rights* (VCDR), an umbrella organization made up of representatives of 24 disability-related agencies and organizations in the state. Additionally, all of

TABLE 6.
Stakeholder Groups Represented at the Initial Meeting

Advocacy Organizations
Audiology
Assistive Technology
Medicaid Staff
Nursing
Parents of Children with Disabilities
Physical Therapy
School Administration (Special Education)
Self-Advocates
Social Work
Special Education
Speech/Language Pathology
State Department of Education Staff
Paraprofessionals
University Faculty
Teachers of the Blind and Visually Impaired

the RSWG's major activities were posted on the internet, courtesy of the *Related Services Research Project* <www.uvm.edu/~uapvt/RSRP.html> at the *Center on Disability and Community Inclusion* at the University of Vermont under the heading "Related Services Work Group." Two links are available: (1) <www.uvm.edu/~uapvt/rsrp/latest.html> for "The Latest" information, and (2) <www.uvm.edu/~uapvt/rsrp/older.html> for "Older Stuff" (e.g., previous meeting minutes, questionnaire results).

During its first year, the RSWG formally met five times, while numerous smaller group and individual activities occurred between meetings. During the final six months, designated members attended to a variety of logistical, research, and writing tasks to ensure completion of the project activities.

ACTIVITIES AND TIMELINES

At the initial meeting of the RSWG two small group activities (20 minutes each) involved participants in sharing perspectives and concerns regarding related services. Groups of five people were asked to use specific collaborative team meeting procedures (e.g., round-robin responding, specific time limits, deferred judgment on statements made) to respond to two statements about related services: (1) "I have a concern that . . ." and (2) "I hope everyone could agree that . . .". Each small group was assigned a facilitator, timekeeper, and recorder who wrote responses on chart paper. Each group reported its results to the whole group, after which a brief discussion ensued and decisions were made about future activities. All records from the small groups were collected, typed, sorted, and categorized.

Based on the input provided by participants at the first meeting, seven primary areas of concern were identified (see Table 7). At a second meeting a month later, participants discussed the categorized concerns and points of potential agreement. The group agreed to use a statewide survey to gain input and to determine which categories of potential action were the highest priorities based on urgency/importance and attainability.

The survey instrument was a questionnaire which requested a small amount of optional demographic information and focused primarily on gathering information about the seven areas of concern identified by the RSWG participants. In reference to each of the seven areas of concern, participants were asked to respond to two prompts: (a) *It is urgent/important*, and (b) *It is attainable*. They were asked to circle a number from 1 to 5 which most closely reflected their opinions, where "1" was anchored with the word "Disagree," and "5" was anchored with the word "Agree." In June 1997, 100 questionnaires were distributed statewide through VCDR and RSWG participants.

TABLE 7.
Areas of Concern for Potential Action

1. Definitions
   There are not widely agreed upon statewide definitions for terms such as "consult," "direct or indirect service," "screening," "educationally vs. medically necessary."
2. Referrals
   There is concern that physicians are making referrals for school-based related services without having sufficient knowledge of educational necessity.
3. Qualified Professionals
   There are insufficient numbers of qualified related service personnel available to meet the needs of students.
4. Common Standards
   There is no widely agreed upon set of standards within the state which summarizes appropriate, promising, and exemplary practices regarding related services (e.g., common goals, decision-making practices, service options, team collaboration, location of services, IEP documentation).
5. Funding
   There is concern that funding sources and school administrative practices, rather than student needs, determine the type and ways in which services are provided.
6. Information Access
   There is concern that parents, general education teachers, other school personnel and community members do not have sufficient access to current information about related services in schools.
7. Evaluation of Impact
   There is concern that there are limited evaluation data regarding the impact of related service provision on students' education.

PUBLIC RESPONSE AND INPUT

Sixty-six percent of the questionnaires were returned. Of those individuals responding to the demographic questions, nearly 73% (n = 43) were female and 27% (n = 16) were male. The largest number of respondents, nearly 44% (n = 29) were identified as *family members/advocates* (e.g., parents of children with disabilities, high school students with disabilities). They were followed by: *related services providers* (e.g., physical therapists, speech-language pathologists) (26%, n = 17); *educators* (special educators, classroom teachers) (17%, n = 11); *unidentified respondents* (9%, n = 6); and *administrators* (e.g., special education coordinators, school principals) (4%, n = 3).

As shown in Tables 8 and 9, respondents indicated that all seven of the areas were important, with the need for "common standards" topping the list. Although dealing with funding issues and the need for more qualified personnel were the next two most urgent/important categories ranked by respondents, these categories were rated lower in terms of attainability.

SELECTING PRIORITIES

The data from the questionnaires were compiled and reported at a subsequent meeting of the RSWG. Group members relied on data from the questionnaires in selecting priorities upon which to act. The group decided to address the three categories of concerns that were most highly ranked as attainable: *Information Access*, *Definitions*, and *Common Standards*.

TABLE 8.
Rankings of Urgency/Importance

	N	*Mean*	*SD*
1. Common Standards	60	4.38	0.78
2. Funding	64	4.36	0.91
3. Qualified Professionals	63	4.29	1.02
4. Evaluation of Impact	58	4.19	1.02
5. Information Access	64	4.16	1.07
6. Definitions	61	3.92	1.05
7. Referrals	59	3.66	1.27

TABLE 9.
Rankings of Attainability

	N	*Mean*	*SD*
1. Information Access	54	4.07	1.11
2. Definitions	55	4.02	0.93
3. Common Standards	53	3.83	1.16
4. Evaluation Of Impact	53	3.81	0.94
5. Funding	52	3.62	0.95
6. Referrals	50	3.60	1.07
7. Qualified Professionals	51	3.41	1.00

ACTION-PLANNING AND DISSEMINATION

By this point, a group of approximately eight people continued ongoing, active involvement in the RSWG. Two subgroups were formed; one to address *Definitions* and the other to address *Common Standards*. *Information Access* would be embedded in the overlapping work of both subgroups. The group decided to develop a manual, *Related Services for Vermont's Students with Disabilities* (Dennis et al, in press), that would address all three substantive areas. The manual would be designed for use by a wide audience (e.g., parents, teachers, advocates, service providers, administrators). It would contain: (a) a legislative context for, and approaches to, providing related services; (b) *Vermont's Guidelines for Related Services* (Common Standards); (c) funding for related services; (d) frequently asked questions about related services; (e) information about 12 related services disciplines (e.g., speech-language pathology, occupational therapy, orientation and mobility, school psychology); and (f) an extensive bibliography. Eighteen individuals, with specific expertise in various areas included in the manual's outline, were recruited to write sections of the manual.

The materials created by the RSWG underwent an internal Vermont Department of Education (DOE) review process and were approved for publication by the Department. The Department would print the documents and distribute them to every school and appropriate agency and organization in the state.

The *Common Standards* subcommittee developed *Vermont's Guidelines for Related Services*, (listed in Tables 1–5) in brochure and poster formats. Initial development of the guidelines was based on extensive review of the professional literature. As drafts were developed, they were posted on the world-wide web and sent to all RSWG and VCDR member organizations for input. A modest but steady stream of feedback was received. After several rounds of revision, the *Guidelines for Related Services* were sent to the DOE for review and editing. The DOE requested that the nearly final version be communicated to family advocates for final review. Families affiliated with *Parent to Parent of Vermont* and the *Vermont Parent Information Network* made final suggestions which included wording changes and sequence rearrangement.

The brochures and posters of *Vermont's Guidelines for Related Services* have been disseminated statewide to all Vermont schools, VCDR member organizations, and other disability organizations. The Guidelines also are posted on web sites: one through the *Center on Disability and Community Inclusion* at the University of Vermont <www.uvm.edu/~uapvt/rsrp/relatedservices.html> and the one through the DOE <www.state.vt.us/

educ/relserv.htm>. The full manual has been approved by the DOE and is currently in press.

IMPLICATIONS

No one involved in this project believes that distributing brochures, posters, or even manuals is sufficient to change practices that are strongly embedded across our state and nation. What we do believe is that the RSWG has demonstrated that issues pertaining to related services are important to parents and service providers alike. Further, the *Guidelines* and other written materials provide a sound basis for discussion among a wide range of people. These discussions will lead, we believe, to greater understanding of the use of related services in ways which are educationally important for students with disabilities and for their families, schools, and communities.

If the ideas presented by the RSWG are to advance beyond discussion and increased awareness, school personnel and families will need to become familiar with the *Guidelines*. This may require regional or district-wide training opportunities or other discussion forums. A simple, yet potentially powerful, next step would be to enable groups in each school district to assess their own status relative to the *Guidelines* by comparing their own practices to those presented as promising or exemplary. This type of self-assessment can provide a focal point for clarifying the meaning attached to the *Guidelines* in various schools and communities. People can develop a shared understanding about the issues, which is essential for genuine collaboration. The self-assessment information can also serve as a source of fact-finding upon which to develop local plans for school improvement activities pertaining to related services.

Ultimately, the aim of the materials developed by the RSWG is to assist families and school personnel in providing quality related services for students with disabilities in ways that are educationally relevant and necessary. Clearly there are other factors which affect this service provision (e.g., availability of service providers, qualifications of staff, sufficient funding). Access to information, however, about promising and exemplary practices that are commonly understood and accepted by educational team members, is a vital building block for assisting students with disabilities to receive a free, appropriate education. These practices, well understood and implemented, will enhance the educational experience of students with disabilities who are educated alongside their peers without disabilities in their neighborhood schools.

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STUDENTS WITH ACQUIRED BRAIN INJURY: THE SCHOOL'S RESPONSE

Ann Glang, George H.S. Singer, Bonnie Todis
Paul H. Brookes Publishing, 1997
399 pages; $29.95

REVIEW

Students with Acquired Brain Injury: The School's Response is an edited book written to provide a resource for educators with particular attention to the transition of students with acquired brain injury from medical to school settings. The editors have a background in special education, qualitative research methodology, and extensive work with children and adults with brain injury. Contributing editors bring a great deal of expertise to the content of the chapters including working with families, neuropsychology, assessment, special education, administration, and brain injury.

Section One of the text provides an overview of acquired brain injury with emphasis on the impact of this disability on the public schools. An important part of this section deals with how families, students, and educators cope with the effects of acquired brain injury (ABI) in educational settings. Throughout the book the importance of families is woven through the discussion of acquired brain injury. An important part of the book provides information about how to recognize and minimize tensions that may occur within the family and between the family and education personnel.

Section One also contains valuable information about reauthorization issues including a discussion of classification of traumatic brain injury. Although this topic is known by many special educators, this information will benefit general education teachers, many of whom will be working with students with acquired brain injury.

A valuable table is provided in Chapter 1, "An Overview of Educationally Relevant Effects, Assessment, and School Reentry," by Bonnie R. Kraemer and Jan Blacher. This table includes appropriate instructional techniques and strategies for students with acquired brain injury. Although the list contains strategies commonly found in professional literature for teachers working with students with brain injury, this particular table provides the information in a concise and simplified document.

Joanne Singer's chapter, "One Mother's Story: Including Her Son in Coma in a General Education First-Grade Class," includes meaningful information regarding the inclusion of a child with a severe brain injury in a general education class. Told in a very readable format, this chapter captured the voices of the parties involved in such a placement. It will assist all educators as well as family members who are involved in planning and implementing such a placement.

The next logical step in the process of providing appropriate services for students with acquired brain injury is found in Section Two, "Planning and Carrying Out Instruction." In this section the three chapters discuss aspects of neuropsychology, assessment, instruction, and transition plans.

As many students with acquired brain injury will be seen by psychologists and/or neuropsychologists prior to their return to school, this chapter is essential in a text such as this because of the important link between the medical and educational worlds. Linking the information obtained from the neuropsychologist with educational plans assists classroom teachers and other professionals in the school setting in developing an appropriate educational plan for students returning to school.

Developing strategies of instruction for students with acquired brain injury is one of the most important components of planning the return to school for students with ABI. The vignettes provided in Chapter 5, "Effective Assessment and Instructional Practices for Students" by Kathleen A. Madigan, Tracey E. Hall and Ann Glang, make the complex task of planning and implementing instruction more meaningful. Posing important questions about the next steps in planning through these case studies causes educators to carefully think through the process of teaching students with ABI. The appendix provided at the end of this chapter includes references and resources to assist educators in specific areas of instruction.

An important part of the book is found in the chapter by Sally Morgan Smith and Janet S. Tyler on successful transition planning. The life-span approach outlined in the chapter provides a framework for the involvement of the many components needed for a student to become successful outside of the classroom.

Section Three, "Social and Behavioral Interventions," contains four chapters emphasizing strategies and interventions to assist teachers and others to deal with behavior and social concerns. This section is particularly important because of the challenges students with ABI have in these areas. Professionals are often more comfortable in dealing with academic concerns than behavior issues and these chapters provide useful insights into social and behavioral concerns.

Chapter 7, "Understanding and Overcoming the Challenging Behaviors of Students with ABI," provides not only an overview of the problems students sometimes experience but an outline of how to develop an effective behavior change strategy. A variety of interventions for challenging behaviors is discussed. Additionally, Chapter 8, "A Positive Approach to Challenging Behaviors," provides an additional approach to dealing with difficult behaviors.

The remaining chapters in this section deal with establishing friendships through the Building Friendships Project as well as other strategies to assist in implementing support for social and behavioral problems through counseling.

The final section, "Parents and Professionals Working Together," is an important section of this book. Without the support of families, educating students with ABI is very difficult. Establishing partnerships between families and educators as well as between groups of educators is critical.

Barbara R. Walker in "Creating Effective Educational Programs Through Parent-Professional Partnerships," provides strategies for working with family members. The table presented in this chapter, "Elements of a constructive professional mindset," is an excellent guide for communicating with family members in an interested, involved manner. Walker's list of constructive and nonconstructive communication skills is helpful in developing good relationships with family members.

Although all areas of this text will assist in the preparation of professionals to work with students with ABI and their families, Chapter 12, "Preparing Educators to Serve Children with ABI," carefully describes the important role that all members of the education team have for students with ABI. Tyler describes possible college course content as well as the importance of the inclusion of field based experiences for preservice students. As institutions of higher education revamp their teacher preparation programs, consideration of information on ABI is critical. Chapter 13 deals with the importance of team based consultation in the ongoing support of professionals in dealing with students with ABI.

The final chapter in the book is an excellent resource. It provides some of the most common questions that may be asked about ABI with corresponding answers. The answers are clear and provide reasonable suggestions for instruction, transition, medical, and social aspects of this disability.

This book could be used as either a textbook or reference book for undergraduate or graduate courses. Additionally, it would be an excellent resource book for public school professional libraries. As more and more students with ABI are being transitioned from medical to educational facilities, this book would serve as an excellent resource prior to and as the transition occurs.

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LIVING WITH SPINA BIFIDA:
A GUIDE FOR FAMILIES AND PROFESSIONALS

Adrian Sandler, M. D.
The University Of North Carolina Press
$45.00 hardcover, 1997 $19.95 paperback, 1997
272 pages

REVIEW

How many doctors or early intervention specialists have faced concerned parents of newborns with disabilities who want to know what their children will be like? Will their son learn to walk or talk? Will their daughter grow up and get married? In *Living with Spina Bifida*, Dr. Adrian Sandler not only explains what spina bifida is but also provides a road map to the birth, growth, and development of children with spina bifida.

Living with Spina Bifida is aimed at a wide audience. Sandler states in the preface that this text is primarily meant to provide parents with needed information; however, the work is also directed at family physicians and related medical personnel. Further, it includes information valuable to teachers and school personnel, vocational rehabilitation specialists, and others who may be called upon to provide services to children and young adults with spina bifida. While reaching an audience this diverse is a lofty goal, Sandler more than met his target. He has highlighted sections of the book aimed primarily at parents or physicians with red or black bands, allowing others to read with some discretion. Nonetheless, even the technical sections are full of useful information and are not overly difficult to read.

The structure of the book is logical and progressive. The first three chapters outline Sandler's philosophy and provide background information on spina bifida. Chapters 4 through 9 address the developmental stages of growth. The final two chapters focus upon family, educational, and work-related issues. The book includes an abbreviated glossary of terms, a reference list of suggested reading, and a worldwide directory of spina bifida associations.

The first chapter provides an overview of the book and explains Sandler's developmental perspective. Educators may initially balk at the stress placed on developmental stages and outcomes in this text. Educators will be well-served by noting that Sandler is writing from a medical model. He states that "independence and self-care skills are acquired in sequence" (p. 5), reflecting a belief in step-wise development. This belief in developmental stages and step-wise accruement of skills will not necessarily be shared by many educators; however, Sandler does not use the developmental perspective to exclude students from activities based on failure to achieve developmental milestones. Rather, his philosophy is one of inclusion and partial participation in instances where total task acquirement is not feasible.

Chapters 2 and 3 describe neural tube defects and their causes. These are the most technical chapters of the book, but the text is aided by a number of well-drawn illustrations. Chapter 2 covers the various types of neural tube defects, how they form, and the range of functional problems associated with spina bifida. Chapter 3, on epidemiology, is firmly grounded in research. Sandler is hopeful that spina bifida is, for the most part, a condition which can be prevented by means of a diet high in folic acid. Some mothers may misinterpret his stance on prevention as criticism of their actions or diets during the first trimester of pregnancy, or worse, overtly blame themselves for their children's disabilities. Educators recommending this book to parents will need to be supportive of them during their reading of this chapter, and prepare themselves for the inevitable questions it raises.

Chapters 4 through 9 take the reader on a journey of growth from pregnancy and birth through adolescence and young adulthood. Chapter 4 begins with a vignette of parents who have just learned that their unborn child will have spina bifida, and proceeds to explain why parents so often have poor first experiences with the medical profession upon learning of their children's disabilities. His advice to other physicians may be particularly interesting—even eye-opening—to those outside the medical profession. Chapters 5 through 9 each cover developmental, habilitation, medical and emotional issues, and end with a parent-to-parent section containing quotes from parents concerning each stage of the child's life.

Chapter 5 discusses the newborn and describes problems encountered during the first week of life. The illustrations, again, are especially good in the medical issues section in helping to explain how the myelomeningocele is closed, how the shunt is inserted and why, and what the Chiari Malformation is and what it means to long-term prognosis. Sandler is particularly adept during each stage of a child's life in discussing urinary, bladder, and kidney problems. He focuses upon the importance of toilet training or management for all children including those with spina bifida, and how toileting management can be accomplished with preschoolers and school-aged children. These chapters also cover such diverse topics as types of equipment which will enter the child's life at various stages of development, feeding problems, learning to dress oneself, hospitalization, latex allergies, sexuality, and driving a car. The progression of topics follows the age of the child.

Of particular interest to the educator reading this book are the Chapter 8 developmental issues section focusing on learning disabilities, and Chapter 11, which focuses on education. Although only an overview, Chapter 8 discusses the types of learning disabilities seen in students with spina bifida, and why these students often fail to qualify for special education services. Sandler addresses many aspects of learning disabilities including verbal versus performance IQ. Spina bifida particularly causes visual-perceptual problems, often resulting in math difficulties. Other learning disabilities include organizational problems, social problems including cocktail party speech, writing problems (dysgraphia), and attention deficit disorder. Sandler includes a sample letter to be used during the referral process for special education services which teachers may find helpful.

Most special educators will not find any new teaching techniques in Chapter 11, although the list of classroom adaptations provided might be of use to the regular education teacher with a student with disabilities included in the classroom. Sandler speaks very positively about early intervention and its impact on young children with disabilities. He provides some wonderful advice to parents including maintenance of school records, what to include on the IEP (including who will assist with catheterization), and how to self-advocate with the school system in a positive manner. Scattered throughout the chapter are several resources which may be of value to the parent, student, or special educator planning for transition from school to work. This chapter is followed by a comprehensive directory of spina bifida associations.

Sandler's obvious concern for families is the most striking aspect of this book. Throughout the text, his focus remains on what is of importance to them. He admonishes his peers to provide family-centered care, advice which educators would as well be wise to heed. He stresses that ultimately, the outcome for the child is dependent upon the support received from her family. His attention to the needs of fathers is illustrative of this attitude, opining that "a lot of fathers report feeling left out of the whole 'parenting thing'" (p. 214), and advising fathers to make their presence felt. At the conclusion of this book, the reader is left feeling that Sandler truly believes and practices a philosophy of interdisciplinary service to families, and partnership between professionals and parents. In all respects, this book is of value to the educator not only as a source of information on spina bifida and as a resource to be shared with parents, but also as a guide to teach interdisciplinary teaming.

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CARING FOR CHILDREN WITH CEREBRAL PALSY: A TEAM APPROACH

John Paul Dormans and Louis Pellegrino, editors
Paul H. Brookes Publishing Co., 1998
$38.95, 496 pages

REVIEW

WHAT I ALWAYS WANTED TO KNOW ABOUT CEREBRAL PALSY AND MORE . . . OR LESS?

Caring for Children with Cerebral Palsy: A Team Approach by John P. Dormans and Louis Pellegrino represents one of the first texts in a number of years to specifically address cerebral palsy (CP). The authors are to be commended for attempting such a comprehensive review of how to provide adequate services to this population of children. After reading the text, from an educator's perspective, I have a number of thoughts about its utility in an educational setting or with families who have children with CP. First, a discussion of the accuracy of the content, specifically as it relates to current recommended practices for children with disabilities, will be provided. Next, how various audiences would benefit from using this to increase their knowledge of CP will be examined. Last, a few comments about the organization of the text will be addressed.

As an educator with 15 years experience working with children who have CP, I was familiar with much of the content provided in the text. Without a medical background, I cannot verify or refute much of the technical information provided throughout the text. Certainly, the biographies of the authors validate their background and knowledge of CP sufficiently to assume that they delivered accurate medical information. I do take exception, however, with some of the statements made throughout the text regarding the education of children with CP. First, the issue of an interdisciplinary approach to "caring" for children with CP requires comment. Clearly, the authors recognize that a team approach is appropriate for working with children who have CP. However, there seems to be an omission of educators in that team approach. It is not until the end of the book (pg. 462) that the importance of collaboration between therapists and educators is stressed. In addition, I take issue with the notion that an interdisciplinary approach is preferred over other team models for providing services. In chapter 3, the authors describe the various team approaches (i.e., multi, inter and transdisciplinary). They state that transdisciplinary services compromise collaboration between professionals and thereby advocate interdisciplinary services as a model. This belief is contrary to what is considered best practice in special education. In fact, a transdisciplinary model is preferred because there is shared responsibility among team members and it results in integrated services and team collaboration (Orelove and Sobsey, 1996; Rainforth & York-Barr, 1997).

A second content issue that requires attention is the numerous references to students with CP who have mental retardation. Beginning in chapter 1, the authors state that severe mental retardation is often associated with CP. Throughout the text there is mention of children with CP having mental retardation or minimal cognitive abilities. What is missing from the text is information on the impact of the physical disability on a child's ability to interact with his/her environment and to communicate. These factors not only adversely effect the child's ability to learn, but more importantly they adversely affect the child's capacity to successfully complete standardized assessments that measure intelligence (McCormick, 1996). There are numerous examples of children and young adults with CP who were thought to have profound cognitive impairments, who, in fact had normal intelligence. This should have been emphasized throughout the book and particular should have been attended to in the chapter on communication.

Clearly, much of the focus of this book was on how to clinically "treat" children with CP. However, I was excited to see the chapters, toward the end of the text, on education, transition and the family. While these chapters provide some useful information, Chapter 18—*The School*, in particular, falls short of highlighting all of the recommended practices in special education. In particular, ecological assessment, person centered planning, activity-based instruction, and family focused programming are notably missing. The authors appropriately identify inclusion as a best practice, but unfortunately indicate that children who are included in general education must also attend resource classes. As well, they distinguish between children with CP who have mental retardation and those who do not, indicating that the latter group are more likely to be included. These statements do not consider the movement in special education toward full inclusion (Falvey, Grenot-Scheyer, Coots, & Bishop, 1995).

While reading *Caring for Children with CP: A Team Approach*, I found myself continually asking myself the question, "If I were an educator (parent, therapist, professor), would this information be useful to me and how would I use it?" There are, in my estimation, five groups who might utilize this text: families, educators, therapists, university faculty, and physicians. Figure 1 lists possible times when the text would prove particularly useful to each of these audiences. As well, Figure 1 provides an example of important information contained within the text that would prove useful to each of these audiences. The figure is not meant to be an exhaustive list, but rather samples of what readers might find, should they decide to use the book to further their knowledge of CP.

There are some organizational issues worth noting. First, the authors utilize numerous diagrams and graphics that serve to support the text's content. For example, in chapter 2 there are graphics that explain the primitive reflexes; these provide the reader with an excellent visualization of each reflex. In some cases, the authors tended to put too much text in the table description, making it difficult to follow. However, as a whole, these graphics made much of the medical information understandable. Second, there is some unnecessary redundancy in the text. For example, there is information on related disabilities in chapter 2 which is repeated (albeit expanded upon) in chapter 4. There is some redundancy between the chapters on nutrition and feeding (chapter 11) and feeding and communication (chapter 14). I would have preferred one whole chapter on communication, as there was important information, such as nonsymbolic communication, omitted from that chapter. Third, considering that the text was almost exclusively written by medical personnel or therapists with a medical background, the authors generally did a commendable job explaining terminology (e.g., when supine is mentioned, there is a definition in parenthesis). Even still, if the authors intended to for this text to be used with a wide audience, a glossary of terms would have proven helpful.

In summary, *Caring for Children with CP: A Team Approach* is a thorough review of all aspects of "clinical" care for this population of children. From an educator's perspective, the text certainly covers all of the physiological needs I have dealt with relative to children with CP. Although there was an attempt to cover all of the issues, the text falls short of adequately covering the educational needs of this population. In his forward, Mark L. Batshaw indicates that this text is useful to all members of the team who provide services to children with CP. This may well be true for the majority of the team who have a medical background. However, for those of us who are seeking a resource for how to a) conduct adequate educational assessments, b) develop communication systems for children who are nonverbal, c) use a piece of

Figure 1

Audience	Suggested Uses When might use	Example from text
Families	• following initial diagnosis • prior to child having surgery • trying to access resources • identifying ways to be involved in their child's care	In the chapter on orthopedic approaches to treatment (chapter 7), families might find the explanations useful in clarifying information delivered to them by a physician. Although it is extremely technical, the supplemental diagrams might serve to facilitate an understanding of the transformation.
Educators	• identifying goals of treatment for spasticity • researching nutritional issues • understanding the impact on function • understanding the role of the family in treatment • adapting and accommodating for teaching daily living skills	The nutritional issues addressed in chapter 11 are extremely important for educators. They often have to prepare meals, feed children or teach them to feed themselves. They need to be aware of the impact of nutritional deficits for a child with CP.
Therapists	Needing resources for: • assessment • treatment • post-operative considerations • equipment • origin of CP	Therapists will find detailed information for providing services to children with CP relative to their discipline (e.g., PT–postsurgical management of spasticity). As well, they will find some useful information on areas outside their discipline (e.g., communication needs of children with CP).

Figure 1

Continued

Audience	**When might use**	**Example from text**
University Personnel	Preservice training	Faculty training speech language pathologists, occupational therapists, physical therapists and teachers might use *portions* of the text to prepare the discipline to work with children who have CP. The following chapters are pertinent to each field: • physical therapy: chapter 8 on gait training and chapter 16 on orthotics management • occupational therapy: chapter 13 on daily living skills • speech/language pathology: chapter 11 on nutrition and feeding and chapter 14 on communication and feeding • teachers: section on adaptive equipment and chapter 15 on assistive technology
Physicians	When patient has CP	In chapter 4 there is a detailed process for how to tell parents about the diagnosis (e.g., set aside sufficient time, meet without the child present, etc.); that is excellent and should be read by all physicians.

equipment to increase a child's participation in an activity, d) teach daily living skills, or e) work as a member of a team to provide services to children who have CP, this text falls short of providing us with that information.

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Reviewed by
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REVIEW OF VIDEOTAPES

CLASSMATES WITH ASTHMA

CLASSMATES WITH DIABETES

A SECRET CALLED HIV

Learner Managed Designs, Inc.
Lawrence, KS 66044
VHS/Manual $99.00; Rental $50.00

Learner Managed Designs, Inc. has assembled a set of three videos that address both the physical and psychosocial aspects of asthma, diabetes, and HIV in school-aged children. These videos (10–12 minutes long) serve as excellent resources for educators, parents, and childcare providers who live and work with these children on a daily basis. Each presentation is packaged with simple, graphic examples of the physiology of the various illnesses, as well as point-by-point information regarding the care of the child. But, what makes these videos first-rate, is the attention given to exemplifying how children with such illnesses are capable of participating in everyday school and community life, given the practice of proper care and management.

The video about asthma commences with the voices of parents speaking about their experiences and feelings related to their children who have asthma. This opening immediately welcomes the viewer in a comfortable, personable manner versus the typical educational video with the voice of a monotonous narrator. From this point on, the viewer's interest is drawn and held. The biological aspects are also engaging, outlined with exceptional graphics. Vivid and simple, the graphics help explain the causes of asthma and describe the physical and behavioral symptoms that preclude an asthma attack.

Preventive and maintenance care has a wonderful spokesperson, Nancy Hogshead, the 1984 Summer Olympian who took home three gold medals. Hogshead demonstrates the use of a peakflow meter that can monitor a child's condition, and indicate when a child should rest or is able to engage in an activity. Yet, most helpful is the enlightenment one receives by learning that a person who has asthma is capable of being an Olympic swimmer. This is a wonderful way to dispel the common thinking that children with asthma are unable to participate in activities and sports with their peers. With proper care and attention, a child with asthma is capable of living a life of normalcy.

Extending beyond the biological aspects, this video has testimonials, given by children who have asthma, on how they get along psychosocially. They speak of their feelings and fears, of what teachers have done to help them and even of what behaviors and statements have made them feel left out and insecure. They speak especially of physical activities and often, they can feel helpless. Ways to help children in such situations are discussed and ideas are offered.

The HIV presentation, as well, offers thoughts and words of advice that gives depth to this illness as something a child *has* and not something a child *is*. As a resource for teachers and school personnel, this video combines five sections of information that cover a range of issues from biology to preventive care. The first part diagrams the process of HIV and how the immune system functions, typically versus when infected. How HIV is transmitted and how it is not transmitted is emphasized heavily. For example, we are told that HIV is not transmitted via doorknobs, swimming pools, shaking hands, or coughing.

Part two focuses on how to deal with bodily fluids, such as blood. It explains universal precautions and demonstrates how to clean a blood spill. Part 3 is an eye-opener for those who are uncertain about confidentiality of records and information that may reveal if a child has HIV. This is a very important area that is not always easy to discuss. Nevertheless, this video conveys the general ideals of establishing confidentiality practices and provides excellent examples of how confidentiality can be broken. This, perhaps, is the most valuable part of this video. For educators, especially, it can ease the fears of how to address the situation of working with children who have HIV without compromising their right to privacy.

Parts 4 and 5 are concerned with preventive care and education. How to keep children healthy, how to protect those who have HIV, and ways to include good health measures in the curriculum throughout the year provide valuable information for readers.

In the diabetes video, everyone's perspective is offered, from the children who have diabetes to their parents, teachers, and the school principal. As the children speak about their experiences, they touch on a number of areas that can easily be misunderstood by teachers and peers who are unfamiliar with diabetes; clarifying various issues such as why there is a need to "snack" during class time and how blood measurement does not need to be a major medical affair.

Typical functioning of human chemistry is discussed and diabetes is presented in detail. Low blood sugar and high blood sugar are defined via visual illustrations. Children who have diabetes describe how they feel when they have low blood sugar, and warning signs are discussed for teachers and parents. A healthcare plan is exemplified for schools who have children with diabetes in attendance. Clear cut and concise, it illustrates how to account for timing and type of snacks, blood measurement, schedule and keeping track of signs and behaviors of the children at various times of the day. In addition, a "buddy system" is included as a way for the child to never be alone in the event of a fainting spell or other emergency. Most significant in this video is the point-by-point illustration of what diabetes is and is not. The graphics and lucid explanations provide the viewer with a well-defined, thorough understanding of diabetes. Myths are highlighted, and differences between the child and the adult experience of diabetes are clearly delineated.

In summation, the misconception that all children with asthma, HIV, or diabetes belong only in special education centers is completely erased as it becomes evident that each of these illnesses is able to be monitored. Learner Managed Designs, Inc. has put forth three videos that offer ample discussion of both the dangerous consequences to poor healthcare and the level of normalcy that is achievable through careful healthcare. Fears and anxieties are confronted while awareness and understanding are well developed. These videos are excellent for inservice programs for teacher-training, and for parenting-care workshops.

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INFORMATION FOR AUTHORS

PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES*
THE DIVISION FOR PHYSICAL AND HEALTH DISABILITIES

PDERS seeks to publish articles that contribute to the field of knowledge about education and related services for individuals with physical, orthopedic or health impairments. The following are considered for publication: empirical research; theoretical perspectives; case studies which address promising practices; innovative instructional practices; and reviews of relevant books, materials and software.

SUBMISSIONS

Manuscripts should be submitted to: Dr. Barbara J. Kulik, 3380 Country Club Drive, Glendale, CA 91208-1718 (Fax 818-541-0663). Four copies of the complete manuscript together with an abstract of approximately 100 words should be submitted for review. All tables and figures should be included with each copy of the manuscript.

PREPARATION

The entire manuscript (title page, abstract, text, tables, figures, and references) should be double-spaced on 8 1/2 x 11" paper with at least a 1" margin on all sides. A cover sheet should include title, author(s) name and affiliation (including statements of credit or research support), address and telephone number of the author to whom correspondence should be directed, and a running head. The abstract should precede the text on a separate sheet of paper and should bear the full title of the article. The running head should appear on all subsequent pages.

Tables and figures should be numbered by separate series and placed at the end of the manuscript. Provide brief notes within the text to indicate where each table or figure is to appear.

Overall style should conform to that described in the *Publication Manual of the American Psychological Association*, Fourth Edition, 1994.

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DIVISION FOR PHYSICAL AND HEALTH DISABILITIES

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PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES

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DIVISION FOR PHYSICAL AND HEALTH DISABILITIES

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PRESIDENT'S MESSAGE

DONALD P. CROSS

DPHD President

We are entering a new century and a new millennium. Many new discoveries have occurred during the past century and certainly during the past 1000 years. Shortly, many of us will travel to Vancouver, British Columbia, to attend the national CEC convention and hopefully, the DPHD business meeting. CEC is in a change process. A new structure has been recommended which will eliminate the Delegate Assembly and Board of Governors. The proposed Executive Board will consist of 21 persons. The Board of Governors will be replaced by a representative board, primarily consisting of division representatives and two representatives from each federation. If you have not done so, please check your issue of CEC *Today* for a formal briefing concerning the proposed changes. Let your DPHD board members know what you think. You will find their addresses (snail mail and Email, as well as phone numbers) in the front of this journal.

What is going to happen in the next century regarding the care and education of persons with disabilities, and specifically, those with physical and/or health disabilities? What will happen to existing legislation protecting the rights of the disabled? Where will the teachers come from? Where will the professors who prepare the teachers come from? As you know, there are shortages of special education teachers. Certification has been modified to reflect more generic preparation, whereby teachers are to care for all categories of children rather than a specific category. Many college and university professors are preparing to retire and the doctoral training programs do not appear to have enough personnel in the training programs to replace those who retire. The recent DPHD Newsletter presented an article discussing certification. There are few preparation programs remaining which prepare teachers to work with persons with physical and/or health problems. Will these too be replaced by more generic programs?

A century ago the issues were related to getting children with disabilities into educational programs. Today, the issues revolve around providing them with appropriate educational programs with teachers and related service personnel who are trained to provide the services. We are still fighting the bat-

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tle for our children and most likely will always have this battle to fight. It is up to you, the membership, to do this. You can by being an active CEC and DPHD member. Be active at your local chapter, division level as well as at the national level. Have you considered running for national office?

In Vancouver, we should see the current state of the art of teaching persons with disabilities. DPHD has an exciting strand prepared, presented by members of the division. Please plan to attend these session. Visit our table in the Exhibition area. Attend the DPHD business meeting and reception and get to know your officers and meet fellow professionals. I know that you, the membership, will continue to be the guardian of our profession and will help it grow through your many efforts and contributions. We will see you in Vancouver.

GUEST EDITORIAL

PENNY SILVA MUSANTE

Joan Wald Bacon Award Recipient

As I look over my "thirty-something" years working in a variety of settings with folks who have significant physical and accompanying multiple disabilities, certain "truths" emerge for me. I will try to share some of them in this article.

I applaud the current emphasis on self-determination and self-advocacy and I feel that these concepts are sorely needed to bring a fulfilled quality of life for folks who encounter such difficult obstacles in their daily lives. I started my career teaching students from pre-school through high school and will someday close it with what I am doing now with adults. So often, I have looked back at what I did in school with my students and reflected on its value for them now that they are adults. At the time it just seemed right to encourage a sense of humor, flexibility, social skills, choice-making, decision-making, problem-solving, risk-taking, and goal-setting while plugging along with the curriculum of academics.

I can say now that the things that have helped my former students the most in their adult lives have little to do with academics, but rather the other areas that I just mentioned.

I remember that our class rule was always to *try*; whatever it was we were tasting, smelling, doing and wherever we were going. It was important to me that my students developed an open attitude (thereby increasing their options), and I always encouraged them to try different things while constantly challenging them with a huge variety of functional activities and experiences from which to choose. I appreciated and fostered their interest in interacting with others with disabilities who had interests and experiences similar to their own. This was contrary to some opinions that interacting with others with disabilities was less desirable than interaction with those who did not have disabilities.

For the last 11 years I have been the Program Director of a community-based adult day program called ALIVE (Actively Living and Involved in a Variety of Endeavors) in the Bay Area in California. It has grown from one site of 12 consumers to two sites serving over 60 people who, despite significant physical disabilities, want to live a fuller life in their own communities. Our emphasis is to open doors for our consumers so that they learn to participate as fully as possible on a daily basis in the same kinds of activities in which their friends, relatives and neighbors do. Very simple. No fancy curriculum required, just go out and live. The job of our staff is to assist where necessary to help our participants to engage in the activities of their choice. When the most basic and essential needs are addressed (toileting, feeding, mobility), then each person can focus on personal goals, hopes and dreams from the simplest to the most grandiose.

When I started ALIVE, I had in mind that folks would come and let us know what they wanted to do and we would do our best to follow through. I had seen so many of my former students without opportunities and I wanted to change that for them and others. What happened with most applicants was a hesitancy or inability to express a choice from their own experiences. Undaunted, we created a menu of some basic activities, trips, opportunities from which they could choose. Many still would or could not choose. I feel that they had learned helplessness and had not had experience in choice-making nor taking charge of their lives in any way. After 11 years using our services, many folks are experts at designing their lives while others still struggle with the challenge.

Disheartening to me is that new consumers coming out of schools where they have been "fully included" are not showing much more of an attitude of owning their lives than those from segregated sites in the past. As far as I can tell, students' unique needs for independent and interdependent living and ADL skills still are not addressed adequately in inclusive settings. What can be done along the way to remedy this? Are schools preparing folks for the realities of their adult life? Are parents/families included in the planning and expectations of their young person's life? Does anyone at school really know what is available in the adult world for folks with significant physical disabilities?

There has been a big shift in the view of funding agencies, who have long been caretakers and advocates for people with disabilities, toward expecting one to advocate for oneself for the services which are needed and wanted. (However, their "wants" are falling by the wayside for economic reasons). This fact makes it ever more crucial that folks become more self-empowered so that they can obtain as much as possible to create a quality life for themselves. Are they prepared to make such vital decisions for their present and future lives? How can we help them?

ALIVE was founded with the idea of an opportunity to LIVE and do what one wants. I was influenced by my work in Supported Employment, which I think is a great idea and works well for many folks with disabilities, but in my experience has not met the hopes of those with more significant challenges. However, there is so much enthusiasm and pressure for the idea of "paid work" in the school settings that many students without much potential for it in today's work world bypass opportunities to "live more fully". By waiting for the paid job that they had been promised in school and that they hear about all around them, they are missing out on activities in their lives which are attainable. This is one of the saddest outcomes of our enthusiasm for expanded vocational opportunities and one of the most difficult for me to conquer. I now say "Why not live a little while you wait for that job of your dreams?" It is still a tough sell. We offer a variety of unpaid work options in the community through volunteerism hoping to provide opportunities to acquire a sense of responsibility and fulfillment that comes from helping others.

My disappointment with Supported *Employment* opportunities is countered with my enthusiasm for Supported *Living* opportunities. We do all that we can at ALIVE to support the training of skills to enhance the ability of our folks to succeed in their living arrangements. We have many consumers with major physical and communication needs who have made the successful move to their own apartments and it has made all the difference in their quality of life. I would like to see the same energy and enthusiasm exerted for the living component that has encompassed the development of supported work.

In adult programs we live with a reality unlike our experience with school supports. We have no one-on-one assistant ratio. Our program is funded on a 1:3 basis, when we are lucky. If we can find a therapist and are able to offer speech therapy/communication help, it is through the use of each participant's MediCal benefit. We use public transportation, fixed route (regular buses) and paratransit. We have no PTs or OTs and no funding for them if we could get them. Wheelchairs and communication devices are paid for by families, MediCal, Regional Centers, insurance, etc., but not by the adult agency. Many folks go years without the appropriate and desperately needed wheelchair or assistive device.

Together we have learned that folks limited by disabling conditions cannot always participate in all activities, and that is just life. It makes us all more alike than different and should not be looked at as a denial of one's rights. There is not one of us who can participate in *all* things. Why not look to the other options to fill our lives rather than putting our energy into the negative struggle for that which is so difficult or impossible to achieve? Pick your battles. Think "Bloom Where You Grow" and "When Life Gives You

Lemons, Make Lemonade." I am not saying to give up, but there is more than academics that are important in the lives of individuals with significant physical disabilities. Encourage these folks to try other things and enjoy all that is available.

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FEEDING STUDENTS WITH DISABILITIES: AN HOLISTIC APPROACH FOR EDUCATORS

DIANNE KOONTZ LOWMAN
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ABSTRACT

Within the education setting, the educator has the primary responsibility for feeding the child with disabilities on a daily basis. Within the capacity, the educator assumes the role of team leader, and uses observational and problem solving skills to coordinate the development of a comprehensive feeding plan. This plan is critical to promote the child's health and growth, and to plan interventions which will, ultimately, facilitate the child becoming as independent as possible in eating and mealtime skills. In this article, the author emphasizes the use of an observational/interview process in gathering as much information as possible about all aspects of the feeding, eating, and mealtime process. By using the questions on the Holistic Feeding Observational Form as a guide, team members can gather information from a variety of sources about: the family's feeding routine, issues, and cultural implications; the presence of any respiratory issues; physical development and positioning during feeding and eating; the child's oral motor and sensory development; and communication, behavioral, and socialization skills during the feeding process.

INTRODUCTION

There is probably no single activity as critical to the health, education, and happiness of children with disabilities as feeding skills. Feeding and eating skills are essential to survival; all persons eat to stay alive and healthy. Difficulties in feeding skills may affect all aspects of the child's life, including growth, learning, communication and interactions with others in the environment (Case-Smith & Humphry, 1996). Feeding skills have a long term effect on the quality of life and on the degree of independence a child is able to achieve (Caretto, Francois, & McKinney, 1996). In the best instances, meals combine the nutrition needed for survival and growth, the opportunities for social interactions, and a chance to become independent. For children with disabilities who also have difficulties with feeding, however, attempting to complete a meal without choking or gagging can be very stressful for both the child and the feeder (Orelove & Sobsey, 1996).

DEFINITIONS

Eating refers to the child being able to actively bring food to his or her mouth independently. Feeding refers to the child being assisted in the activity of eating (Avery-Smith, 1996). Oral-motor control relates to the child's ability to use the lips, cheeks, jaw, tongue, and palate (Wolf & Glass, 1992). Oral-motor development refers to feeding, sound play, and oral exploration (Morris & Klein, 1987). Feeding is a part of oral-motor skills, but there are oral-motor skills which may not involve food at all, such as oral motor awareness and exploration (Clark, 1993). The information presented in this article focuses on oral-motor skills as related to feeding.

PREVALENCE OF CHILDREN WITH FEEDING DIFFICULTIES IN THE CLASSROOM

In 1990, Blackman estimated that 25% of children with disabilities consumed an inadequate diet, 90% had some type of nutritional problem, and 15–25% had a weight-for-length ratio below the fifth percentile. Blackman further estimated that 70% of children with developmental delays had some form of feeding problem. In a study of children with cerebral palsy between the ages 12 to 72 months, Reilley, Skuse, & Poblete (1996) found that 36% of the children had severe oral motor dysfunction, 21% had moderate dysfunction, and 34% had mild impairments. Feeding problems may be caused by a variety of conditions or factors including neurologic problems (such as cerebral palsy), congenital anomaly syndromes (such as Down syndrome), gastrointestinal disorders (such as gastroesophageal reflux), metabolic disorders (such as PKU), intrauterine growth retardation (such as fetal alcohol syndrome), chronic illness (such as cystic fibrosis), environmental influences (such as prenatal exposure to substances), and psychosocial factors (such as failure to thrive) (Batshaw, 1997; Berkow & Fletcher, 1992; Klein &

Delaney, 1994; Singer, 1991; Starrett, 1991 and Walter, 1994). In fact, many childhood diseases and disabilities have the potential to negatively affect feeding (Bazyk, 1990). Clearly, there are a significant number of children attending school who require some form of assistance because of feeding difficulties.

In the school setting, classroom teachers and assistants are responsible for feeding a growing number of children with disabilities who also have feeding problems. However, many teachers and assistants report that they felt unprepared to deal with oral-motor feeding problems in the classroom (Lowman & Murphy, 1999). Because of the growing number of children with feeding difficulties in the classroom, preservice teacher training programs in disabilities areas such as early childhood special education (ECSE) and severe disabilities have begun to address feeding difficulties. However, anecdotal data from educators indicate that most knowledge on feeding is still gained "on the job." In a study of 234 ECSE teachers, Lowman (1993) found that 78% of the teachers conducting gastrostomy feedings in the classroom setting indicated their training was received through inservice or demonstration.

UNDERSTANDING FEEDING SKILLS FROM DIFFERENT PERSPECTIVES

In addition to the direct responsibility for feeding children in the classroom, educators are also important members of the planning team. Difficulties in the feeding process may be complex and require planning by a team of individuals from various disciplines (Hall, Yohn, & Reed, 1992). Educational team members come from a variety of disciplines, including but not limited to occupational, physical, or speech therapists, nurses, dieticians, special educators, and family members. Each member of the team approaches feeding issues from a slightly different perspective.

THE CHILD'S AND THE FAMILY'S PERSPECTIVE

The feeding process is critical for family members. Feeding and eating difficulties that affect the child's health, growth, and well-being can be extremely upsetting for caregivers; inability to successfully feed their own child can be a devastating experiences for caregivers. In addition to the nutritional aspects, the feeding process is a social process which helps caregivers and family members form relationships and impart culture, traditions, and values (Case-Smith & Humphry, 1996). Disruptions in the feeding process can upset parent-child, family, and mealtime interactions.

THE EDUCATOR'S PERSPECTIVE

It is critical for educators working with families to first recognize and acknowledge the emotional impact of feeding problems can have on the family. Educators must also respect that individual families have different methods of coping with stressful situations. In addition, educators must remember that while teachers, therapists, and services will change and vary over the child's life span, family members are the constant in a child's life (Shelton & Stepanek, 1994). The family's mealtime routine must be respected and preserved. Because cultural aspects are present in all interactions with children and families, the cultural implications should be a pervasive consideration in all aspects of working with children (Lowman & Lane, 1999). Before making any recommendations or developing the feeding plan, educators should be sure to determine if their recommendations respect the family's beliefs and values.

THE THERAPISTS' PERSPECTIVE

The two therapists who usually are responsible for the development of feeding plans are occupational therapists (OTs) and speech-language pathologists. The American Occupational Therapy Association (AOTA) has issued a position paper on eating dysfunction which states that "because eating is an important daily living skill, essential to health and well-being, and critical throughout a person's life span, it falls within the occupational therapy domain of concern" (Avery-Smith, 1996, p. 846). AOTA summarizes that OTs may be involved in the planning for and development of a feeding plan, as well as in direct evaluation and intervention of feeding difficulties. Oral motor feeding, however, is viewed as a speciality and not an entry level skill. Many newly trained OTs do not have extensive training in oral motor feeding difficulties.

In a document defining the scope of practice of speech-language pathology and audiology, the American Speech-Language-Hearing Association (ASHA) stated that the practice of speech-language pathology includes: "Screening, identifying, assessing and interpreting, diagnosing, and rehabilitating disorders of oral-pharyngeal function (e.g. dysphagia) and related disorders" (ASHA, 1990, p. I–22). In the practice of speech-language pathology, oral motor feeding is usually viewed as a speciality and not an entry level skill.

THE HEALTH CARE PRACTITIONER'S PERSPECTIVE

Members of the educational team who are trained in health care include: the nurse, the dietician, the occupational therapist, the physical therapist, and

TABLE 1.
Ten indicators of aspiration include:

1. Medical history (pneumonia, bronchitis, asthma);
2. Dramatic events have happened (food stuck in throat, required Heimlich);
3. Not enough intake of liquid (history of dehydration);
4. Cough, gagging, or choking;
5. Wheezing or asthma;
6. Rapid breathing or fatigue with meals;
7. Vomiting or regurgitation;
8. Drooling or food falls out of mouth;
9. Spurting or forceful ejection of food;
10. Mealtime behaviors (such as fear, reluctance, eats slowly, eats in unusual way).

Taken From: Hall, S., Yohn, K., & Reed, P. R. (1992). *Feeding students in school: Providing guidelines and information on safe feeding practices for special students.* Salem, OR: Oregon Department of Education.

the speech-language pathologist (Hall, et al., 1992). If these individuals are not satisfied with the information available in the school's medical records or if they suspect specific medical concerns such as malnutrition or aspiration due to swallowing difficulties, a comprehensive medical evaluation may be recommended. Members of a medical pediatric feeding and swallowing disorders' team may include a pediatric gastroenterologist, a developmental pediatrician, a diagnostic radiologist, a dietician, or a nutritionist (Hall et al., 1992; Walter, 1994). The primary role of this medical team is to determine what is "safe" for each child and to provide that information and educate those providing direct care for children with feeding problems (Walter, 1994).

Ultimately, the individuals who have the primary responsibility for feeding the child on a daily basis will be family members, the teacher, and the classroom assistant. For this reason, the educator assumes the role of team leader within the educational setting. In this capacity, educators need the skills to coordinate the development of a comprehensive feeding plan. The process described in this article is designed to be a tool to assist in the development of good observational skills and problem solving skills related to feeding problems.

DEVELOPMENT OF THE HOLISTIC FEEDING PLAN

Since feeding and eating are dynamic skills, this article emphasizes the use of an observational/interview process to gather as much information as possible about all aspects of the student's feeding, eating, and mealtime process. The *Holistic Feeding Observation Form* in the Appendix is a problem-solving format which helps team members consider all components which might interfere with feeding, eating, and mealtime (Lowman & Murphy, 1999). By using the questions on the Holistic Feeding Observation Form as a guide, team members can gather information from a variety of sources about:

- the family's feeding routine, issues, and cultural implication;
- issues in feeding during the day;
- the presence of any respiratory issues;
- physical development and positioning during feeding and eating;
- the individual's oral motor and sensory development;
- communication, behavioral, and socialization skills during the feeding process; and
- the individuals' skill level and goals related to independence and eating/self-feeding.

COLLABORATION WITH THE FAMILY

The first step in the development of a holistic feeding plan is to start communicating with the family. Determine if they have established a feeding routine and understand what this routine involves. Specify what aspects the family would like to keep, what they would like to change, and what they would like to discard. It is critical to note the pleasurable aspects of the feeding process, not to interfere with these, but rather build on their positive contributions to the feeding process (Lowman & Lane, 1999).

It is important to understand the specific issues identified by the caregivers who feed this child. The team should consider the priorities set by the family and, when possible, establish these as priorities for the feeding plan. There may be times when, for health and safety reasons, this is not be possible. In these instances, the team must address these issues with the family and establish priorities which are safe and which promote the child's health (Lowman & Lane, 1999).

Cultural implications should be considered in all aspects of observing, planning, and working with children with feeding problems. Collaboration with the family involves acknowledging and accepting the cultural values of the family. Before developing any specific feeding plan, the team must determine the family's cultural norms for food type, food preparation, using utensils, time of meals, talking during mealtimes, or eating with the family. Confer with the parents to ensure that the team's suggestions are consistent with the family's beliefs, values, and priorities for the child (Lowman & Lane, 1999).

OBSERVATION OF COMPONENTS OF EATING/FEEDING PROCESS

The second step in planning for a child with feeding and eating problems is to be sure to observe all components of the mealtime process and to rule out any health or functional problems.

Respiration. Respiratory problems can have serious health and safety implications and should always be evaluated by members of the health care team. Some observations which should be noted include the presence of an over or under responsive gag reflex, an inhibited or delayed swallow reflex, and swallowing with gagging, coughing, or aspiration. For each child, determine who sets the feeding pace, the child or the feeder, and if the pace allows extra time for coordination of breathing and swallowing. It is especially important to note the child's ability to coordinate breathing, swallowing, and talking; children who have difficulty integrating a coordinated swallow and breath are in danger of aspirating food and ultimately of inadequate intake of nutrients required for growth (Wolfe & Glass, 1992). Educators who are feeding children with possible respiratory problems should be familiar with the indicators of aspiration (Hall, et al., 1992). Problems with any of these should be referred for a medical evaluation.

Sometimes children will have respiratory problems severe enough to warrant specialized health care. These children may have a tracheostomy, be fed through a tube, or must be monitored closely for aspiration. The completion of a Health Services Plan is especially helpful in specifying warning signs and emergency procedures for children who have respiratory problems (Lowman, 1998; Lowman & Lane, 1999; Lowman & Murphy, 1999).

Oral motor development. Consult with the speech and/or occupational therapist to establish if the child's overall muscle tone has been determined (e.g. normal, high, low, fluctuating). Note which activities help normalize the child's overall tone. Also determine if there are specific tone issues related to the face and mouth musculature. Ask the therapist if needs for oral motor treatment been identified. Some common examples include: jaw (thrust, clenching, retraction, instability), tongue (retraction, thrust, limited movement), lip and cheek (low tone, lip retraction), and palate (nasal reflux, cleft). Note if any internal and external methods for providing oral support are currently being used (Lowman & Murphy, 1999).

Physical development/positioning. The position of the child for feeding and eating is critical. Key points to note during observation include these aspects: the head upright and at midline; shoulders and arms in neutral or slightly forward; hips, knees, and ankles flexed to approximately 90 degrees; and feet flat on the floor or on a foot rest (Lowman & Lane, 1999). In addition, note the seating position(s) and equipment which is currently being used, and the apparent effectiveness of this equipment. For example, is the child fed sitting on a chair, in a high chair, in a car seat, in the travel chair, on the parent's lap, etc. Which position/equipment appears to be most effective? Which position/equipment does the family prefer? As has been stated earlier, always consult the physical and/or occupational therapist before observing and reporting the child's positioning. The therapist can identify if the child has any physical conditions which must be considered in positioning. In addition, the therapist can identify if the current position is appropriate for the child's needs and facilitates normal tone.

Sensory development. Note any limitations of the sensory modalities: visual, auditory, tactile, gustatory, olfactory, proprioceptive. Then, consider the child's reaction to sensory input in the mouth and around the face. Many children with feeding difficulties show sensory sensitivity to textures, tastes, temperature, and touch. Note the presence of any of the following: refusal of specific foods, picky eating, gagging, vomiting, stuffing food into mouth, and sucking rather than chewing food. Also note where the child places or stores the food in his/her mouth. Examine the 4Ts: texture, tastes, temperature, and touch (Lowman & Murphy, 1999). Determine which textures are most easily tolerated (thick liquids, thin liquids, smooth solids, lumpy solids, chewy solids, crunchy, mixed textures). Which tastes are most easily tolerated (likes vs. dislikes)? What *temperatures* are most easily tolerated (note preferences)? What type(s) of *touch* are most easily tolerated (arousing vs. calming)?

Communication, behavioral and socialization skills. At the heart of successful mealtimes is a respectful interaction between the child and the person feeding the child. This can only be accomplished through communication. Communication takes place through the use of sounds, words, gestures, facial expressions, body language, physical contact, and many other behaviors (Orelove & Sobsey, 1996). Through observation, note how the child communicates: hunger (with food present and with food not present), the need for a change of pace/pause, a choice of food or liquid, readiness for more, and finished? Does the child have the maximum control possible of the feeding interaction? Is the feeding interaction pleasurable?

Transition from tube feedings to oral feedings. The prolonged use of tube feeding can delay the development of oral feeding skills, especially if the child has been fed exclusively using tube feedings without concurrent oral-motor stimulation (Luiselli & Luiselli, 1995). Moving from tube feedings to oral feedings must be done slowly and with respect for the child's needs and abilities; tube feedings should never be eliminated suddenly from the child's feeding regimen (Morris, 1987). A carefully designed transition plan should be developed by the team, including the parents, considering (Wolf & Glass, 1992):

- Child's readiness for oral feedings (including understanding the original medical conditions which resulted in tube feedings);
- Parental wishes regarding transition to oral feedings;
- Level and quality of the child's oral-motor abilities;
- Status of the child's swallowing abilities;
- Child's nutritional needs;
- Normalization of hunger/satiation cycles, and
- Behavioral issues related to oral feedings

A key feature of any intervention program designed to facilitate transition to oral feedings is oral-tactile normalization (Wolf & Glass, 1992). Techniques to deal with the sensory aspects of feeding will be especially useful. In addition to sensory opposition to oral feedings, many children who have prolonged tube feedings also have developed a behavioral opposition to oral feedings. The behavioral strategies will also be helpful. The transition from tube feedings to oral feedings can be a very slow and deliberate process.

THE IMPLEMENTATION PLAN

The holistic process described in this article involves a team of professionals conducting observations and interviews in a variety of settings across time. After these observations and interviews have gathered needed information, the team is ready to begin developing a feeding plan. This process requires the integration of all components into one comprehensive feeding plan (Lowman & Murphy, 1999). During the development of the feeding plan, the following issues must be addressed:

- Including the family, the child, all persons responsible for feeding, and needed specialists in the development of this plan;
- Requesting and incorporating medical and dietary information (including physician orders and nutrition requirements) into the feeding plan;
- Establishing the most effective position, sequence, and procedures for the feeding/mealtime process; and
- Determining the need for feeding equipment.

In addition, the plan should also address procedures and equipment which facilitate eating/self-feeding skills which are as independent as possible.

SUMMARY

Educators are being asked to feed increasing numbers of students with disabilities who have unique problems related to eating and nutrition. In this article, an on-going, structured process of gathering and using information from a variety of sources concerning the family, health issues, procedures, and related communication, behavioral, and socialization skills is proposed. This process has involved a team of individuals, including the family and child. The goal of this process is to make feeding children with disabilities as safe and pleasant as possible for both the child and the adult responsible for the feeding.

APPENDIX

Holistic Feeding Observation Form

Child's Name:	Age:
Date Observed:	Time:
Setting Observed:	Observer(s):

The questions provided under each heading are suggestions to help guide your observations.

I. Collaboration with the Family

- Has a positive family dialogue been established?
- What is the feeding routine: at home? in the school or center?
- Issues identified by the caregiver:
  What is pleasurable specific to the feeding interaction?
  What is difficult specific to the feeding interaction?
- What cultural implications are important to consider?

II. Respiratory Issues

- Is the gag reflex present and effective (not over or under responsive)?
- Is the swallow reflex present and effective (not inhibited or delayed, no paralysis)?
- Is the feeding pace determined by the child (not the feeder)?
- Is swallowing relaxed and without gagging, coughing, or aspiration?
- If a respiratory infection is present, is enough extra time allowed for coordination of breathing and swallowing?
- Is the coordination of breathing, swallowing, and talking difficult?

III. Oral Motor Development:

- Has overall muscle tone been determined (normal, high, low)?
- Have tone issues specific to the face and mouth been determined?
- Have needs for oral motor treatment been identified? Some common examples include:
  JAW: thrust, clenching, retraction, instability
  TONGUE: retraction, thrust, limited movement
  LIP and CHEEK: low tone, lip retraction
  PALATE: nasal reflux, cleft
  OTHER:

IV. Physical Development/Positioning:

- Is optimal postural alignment achievable?
- Are feet and arms supported by a flat surface (not dangling)?
- Is there adequate flexion at the knees?
- Are hips resting symmetrically against a supportive surface?
- Is trunk upright and symmetrical?
- Is a neutral head position assured for most effective swallow and eye contact?

V. Sensory Development:

- Are any limitations of the sensory modalities present: visual, auditory, tactile, gustatory, olfactory, proprioceptive?
- Which *textures* are most easily tolerated: thick liquids, thin liquids, smooth solids, lumpy solids, chewy solids, crunchy, mixed textures?
- Which *tastes* are most easily tolerated (likes vs. dislikes)?
- What *temperatures* are most easily tolerated (note preferences)?
- What type(s) of *touch* are most easily tolerated (arousing vs. calming)?
- Have nutritional needs been addressed?

VI. Communication, Behavioral, and Socialization Skills

- Does the child have the maximum control possible?
- How does the child indicate hunger: food present? not present?
- How does the child indicate need for a change of pace/pause?
- How does the child indicate a choice of food or liquid?
- How does the child indicate readiness for more?
- How does the child indicate when finished?
- How does the child indicate desire for social closeness/distance?

VII. Transition From Non-Oral Feedings to Oral Feedings

- Why was the child originally placed on tube feedings? Have these reasons been resolved? Has medical clearance been given to begin oral feedings?
- Has the feeding team developed a plan to transition to oral feedings? Does the plan address scheduling, current sensitivities, quality vs. quantity, etc?
- Has a Health Services Plan been developed?

VIII. Feeding Process and Implementation Plan:

- Has the family, all feeders and needed specialists participated in the development of this plan?
- Has needed medical information (including physician orders and nutrition requirements) been received and factored into this feeding plan?
- Has needed feeding equipment been identified and obtained?
- Has the most effective sequence been determined?

Adapted from Lowman, D. K., & Murphy, S. M. (1999). *The educator's guide to feeding children with disabilities*. Baltimore, MD: Paul H. Brookes Publishing Co.

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EXPLORING ROLE RELEASE IN THE MULTIDISCIPLINARY TEAM

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ABSTRACT

Collaboration across disciplinary boundaries, particularly in the form of role release, is an essential element of effective teams who serve children and youth with disabilities. The purpose of this article is to describe the responses of veteran team members, a group of special educators as well as a group of occupational and physical therapists, who were asked to identify which elements of their respective disciplines they would be willing to share with one another. The responses of these team members were obtained through their completion of questionnaires organized according to a number of Professional Practice Themes (Disciplinary Content, Assessment and Planning, Program Implementation, Program Planning). The team members responded to clusters of related questionnaire items describing particular elements of their disciplines and indicated whether they would be willing to share the content, in whole or in part, with their colleagues. Both groups of respondents expressed support for role release on more than 50% of the questionnaire items, although there were some differences in the pattern of the responses between the two groups. The implications of these data for the ongoing dialogue around how to meet the challenge of effective teamwork are explored.

Collaboration and teamwork are viewed by many to be a hallmark of effective education for children and youth with disabilities, for those who are at-risk for disabilities, and especially for students whose multiple needs may best be met through the collective expertise of a range of professionals (Givner & Haager, 1995; Johnson & Pugach, 1996; Lipsky & Gartner, 1997; Stainback & Stainback, 1996; Vandercook & York, 1990; Villa, Thousand, Stainback, & Stainback, 1992). Although there is a widespread assumption that teamwork is a promising practice in educational and related services, the actual practice of effective teamwork continues to be a challenge (Utley, 1993). As so aptly stated by Hutchinson (1978) in the early literature on team functioning, "calling a small group of professionals a team does not make them so" (p. 70).

A number of authors have described the history of teamwork over time. Most of these authorities describe this evolutionary process as beginning with multidisciplinary teams (Hart, 1977; Sirvis, 1978) moving to use of interdisciplinary teams (Campbell, 1987; Sternat, Messina, Nietupski, Lyon, & Brown, 1977), and finally to the transdisciplinary model (McCormick & Goldman, 1979; Orelove & Sobsey, 1996). A central characteristic that has differentiated the various forms of teamwork over time has been an increasing degree of *integration* in the nature of the work of teams. The descriptions of what team members do ranges from carrying out the practice of their respective disciplines in isolation from one another (McCormick & Goldman, 1979; Sirvis, 1978) to the *teaching team model* described by Thousand and Villa (1990). These authors describe the teaching team model as "the distribution of responsibility among team members for planning, instruction, and evaluation for a common set of students" (p. 153). Despite extensive efforts to distinguish interdisciplinary from transdisciplinary teams, however, it has more recently been suggested that teams be described in terms of *how* they function as opposed to how they label themselves (Robinson, 1997).

In addition to the degree of integration team members experience in the practice of their professions, it is essential as well that a number of *processes* be addressed to promote effective teamwork. Some of the factors identified in this regard include the necessity for team members to have a shared vision, a common set of underlying assumptions and values, common language, and mutual respect (Giangreco, Cloninger, & Iverson, 1993; Givner & Haager, 1995). Additional processes include the ability to implement the *mechanics* of teamwork effectively such as the ability to plan and implement effective meetings (e.g., specify roles, prepare agendas in advance, adopt guidelines for decision making, etc.) (Givner & Haager, 1995). Indeed, there is general agreement on those characteristics that contribute to team effectiveness (Johnson & Johnson, 1987; Thousand & Villa, 1990). Fundamentally, effective teams are the adult analogue of successful student cooperative learning groups. In this analogy, the five elements of effectiveness include: 1) face-to-face interactions; 2) interdependence; 3) small group social skills in leadership, communication, trust building, decision making, and conflict management; 4) periodic assessment of how well the group is functioning, as well as planning for further improvement in this regard; and, 5) individual accountability for personal responsibilities. The second of these five elements, positive interdependence, involves recognition among the team's membership that no one person can effectively respond to the diverse needs of the students served. Further analysis of positive interdependence in adult teams suggests that the distribution of leadership responsibilities and decision making power must happen among *all* team members. Deciding the who, what, where, when, why, and how of service provision, however, requires that the roles each team member fulfill be clarified. True positive interdependence also requires that team members arrange to share their expertise with one another.

Exploration of the necessity to share expertise leads us again to Hutchinson (1974) who first described this process as *role release*. She viewed role release as a way for team members to exchange, release, and support each other's roles; a process studied later by Lyon and Lyon (1980) and defined by these authors as the deliberate process of "sharing and exchanging information and skills across traditional disciplinary lines" (p. 250).

Lyon and Lyon (1980) conceptualized role release as occurring across multiple levels beginning with general information, proceeding through informational skills, and concluding with performance competencies. Level one, general information, involves communication between two or more team members about basic procedures or practices. An example is a physical therapist describing the manifestations of various forms of neuromuscular involvement to other members of the team. The first level of role release may be viewed as a way to share basic knowledge; to establish or increase understanding or awareness among a group of people. Level two, informational skills, is described by Lyon and Lyon (1980) as the process of teaching others to make specific judgements or decisions. An occupational therapist teaching a classroom teacher to determine whether a hand splint has been applied correctly is an example of an informational skill. Sharing at this level implies that the framework for evaluating the effectiveness of a particular element of disciplinary expertise is transmitted across disciplinary boundaries; it does not, however, imply that the recipient of the skills knows how to carry out the competency. At this point in the progression of sharing disciplinary expertise, the occupational therapist may have fulfilled the expectations for positive interdependence by sharing the factors used to assess correct splint application. Nonetheless, there is no assurance at this point that the teacher will be able to apply the splint correctly.

The third level of the model articulated by Lyon and Lyon (1980) is described as providing support to fellow team members in the acquisition of performance competencies. This level requires that a professional prepare other team members to perform specific actions related to a discipline. An example of a performance competency is a special education teacher sharing positive behavioral support strategies with a physical therapist who, in collaboration with the whole team, serves a child with a severe, challenging behavior. Again, a value for positive interdependence suggests that the teacher support the physical therapist's acquisition of differential reinforcement, for example, so the child's program may be implemented consistently across the school day. The third level of role release may be controversial, as some professionals may be unwilling to share some elements of their expertise, or may be legally prohibited from doing so (Lyon & Lyon, 1980).

More recent work on the concept of role release has been pioneered by Woodruff and McGonigel (1988). These authors describe a process, role transition, through which transdisciplinary team members can teach and learn across traditional disciplinary boundaries. In this model, role transition is described as having six separate but related steps, organized sequentially (Orelove & Sobsey, 1996; Utley, 1993). Role release, as defined within this model, is one of the six processes, although Woodruff and McGonigel (1988) describe it as the most challenging step for teams to implement.

Clearly the extensive literature to date regarding collaborative teamwork has resulted in the identification of many factors related to effective educational and related services. What the literature has lacked, however, is the opinion of practicing professionals on what specific dimensions of their professional expertise they are willing to share in attempting to meet the needs of children and youth with multiple disabilities. The assumption that team members *must* share their expertise has not previously resulted in an examination of which specific elements of professional knowledge and skills may be willingly transferred across disciplinary boundaries, and which elements some professionals may choose to retain. The present study describes the perspectives of practicing professionals from special education, as well as occupational and physical therapy, on the process of role release. A questionnaire was used to examine the views of these professionals regarding the elements of their disciplines they *will*, and *will not* release, to their team members in their collective pursuit of positive interdependence.

METHODS

PARTICIPANTS

The professionals who participated in this study are 17 special educators and 9 occupational and physical therapists who were employees of two agencies in Western Pennsylvania. One agency served children with disabilities of preschool age under a contractual agreement with the Department of Education in the Commonwealth of Pennsylvania. The second agency, whose employees served children and youth of school age, was an Intermediate Unit. Intermediate Units are the middle tier of a three tiered public educational system in the Commonwealth of Pennsylvania. Each Intermediate Unit is comprised of representatives from neighboring school districts who collectively provide some services to students with low incidence disabilities, and provide technical assistance to teachers and other professionals in the delivery of educational and related services. Professionals from both agencies collaborated on a federally funded, three-year project designed to promote the application of innovative practices in collaborative teamwork. The participants had served children and youth with disabilities and their families for an average of 14 years; the range of experience was 2–27 years.

QUESTIONNAIRE DEVELOPMENT

The perspectives of the participants were obtained through completion of questionnaires designed explicitly for the purpose of examining their willingness to share specific elements of their professional expertise. The content of the questionnaires was based on a review of the literature in special education as well as physical and occupational therapy. The content of an early draft of the questionnaire was supplemented with input from various professionals, including the first author and several study participants.

The questionnaires consisted of four major sections, each describing a particular *theme of professional practice* in special education or occupational and physical therapy. The themes of professional practice consisted of: 1) disciplinary content; 2) assessment and planning; 3) program implementation; and, 4) program administration. The four themes of professional practice were further organized into multiple *theme components* focusing on a particular element of professional expertise. An example of a theme component in the special education questionnaire is *functional curriculum*; an example in occupational and physical therapy is *muscle tone*. The questionnaire on special education best practices consisted of 157 items distributed across the four professional practice themes; the questionnaire on physical and occupational therapy consisted of 72 items organized into the same four themes. Table 1 contains a description of the organization of both questionnaires according to the four professional practice themes, as well as the more detailed theme components.

In addition to the organization of questionnaire items into professional practice themes and more descriptive theme components, a set of related

TABLE 1
Organizational Structure of the Questionnaires into Four Professional Practice Themes

Questionnaire on Special Education Best Practices

Title of Professional Practice Theme	Title of Theme Component	Number of Items
Disciplinary Content	The Science of Human Behavior (e.g., the A-B-C paradigm, instructional design including task analysis, cues and prompts, stages of learning, positive behavioral support, etc.)	109
	Functional Curriculum	12
	The Partial Participation Principle	6
	Infused Skills	6
	Chronologically Age-Appropriate Instructional Materials	6
Assessment and Planning	Plans and Conducts Assessment	3
	Synthesizes Assessment Results	5
	Program Planning	3
Program Implementation	Classroom/Community-Based Service Delivery	3
	Home-School Partnership	2
Program Administration	Implementation of Ongoing Communication	2

TABLE 1—*Continued*

Questionnaire on Occupational and Physical Therapy

Title of Professional Practice Theme	Title of Theme Component	Number of Items
Disciplinary Content	Sensory Factors Related to Posture and Movement	5
	Muscle Tone	4
	Range of Motion	8
	Muscle Strength and Endurance	6
	Posture/Postural Alignment	9
	Balance and Automatic Movement	7
	Functional Use of Movement	7
	Materials and Task Adaptation	6
Assessment and Planning	Plans and Conducts Assessment	3
	Synthesizes Assessment Results	4
	Program Planning	3
Program Implementation	Direct Service Delivery	3
	Indirect Service Delivery	3
	Home-School Partnership	2
Program Administration	Implementation of Ongoing Communication	2

items within a theme component were sequenced to reflect various *levels* of role release. Each set of related questionnaire items began with general information, followed by informational skills, then performance skills; and in some cases, problem solving skills. Table 2 contains sample items from both questionnaires that illustrate the various *levels* of the items. The levels were created so that study participants could differentiate between a series of related items and indicate either their willingness to share across all levels, or to withhold certain levels of information within the confines of their own disciplines. In this way specific differences in role release within and across themes and levels could be determined.

TABLE 2
Samples of the Questionnaires Illustrating the Sequenced Levels of Role Release

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Questionnaire on Special Education Best Practices (Professional Practice Theme 1—Disciplinary Content)

Theme Component—the Science of Human Behavior, Items 8–13)

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8. Knowledge of various antecedent events (the "A" in the behavioral paradigm) and how these events can influence human behavior (Antecedent events may include such examples as the salience of sensory stimuli, therapeutic positioning, etc.) (GENERAL INFORMATION)
9. The ability to recognize the effect of various antecedent events on human behavior in application. (INFORMATIONAL SKILL)
10. The ability to design instructional interactions that reflect generalized sensitivity to, or incorporate modification of antecedent events. (PERFORMANCE SKILL)
11. The ability to implement instructional interactions that reflect generalized sensitivity to, or incorporate modification of antecedent events. (PERFORMANCE SKILL)
12. The ability to evaluate the need for modification in the design of instructional interactions with regard to various antecedent events as a result of improvement/no improvement in the learner's behavior. (PROBLEM-SOLVING SKILL)
13. Other (please describe):

Questionnaire on Occupational and Physical Therapy (Professional Practice Theme 1—Disciplinary Content)

Theme Component—Material and Task Adaptation, Items 47–52)

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47. Knowledge of the multiple applications of adaptive educational aids (e.g., a specialized eating utensil, adapted sports equipment, a switch interface) that may enhance an individual's performance of a functional activity (GENERAL INFORMATION).
48. The ability to recognize factors that guide selection/design of adaptive educational aids that may enhance an individual's performance of a functional activity (INFORMATIONAL SKILL).

TABLE 2—*Continued*

49. The ability to design tasks that include the use of adaptive educational aids that may enhance an individual's performance of a functional activity (PERFORMANCE SKILL).
50. The ability to implement tasks that incorporate the appropriate use of adaptive educational aids that may enhance an individual's performance of a functional activity (PERFORMANCE SKILL).
51. The ability to evaluate the appropriate use of adaptive educational aids (or recognition of the need for consultation from a physical and/or occupational therapist) due to improvement/no improvement in an individual's use of adaptive educational aids to perform a functional activity (PROBLEM-SOLVING SKILL).
52. Other (please describe):

RESULTS

SPECIAL EDUCATION BEST PRACTICES

A threshold of 13 of 17 (76.4%) respondents was designated as indicative of a willingness to share the disciplinary expertise specified in a questionnaire item. Using this as a criterion, the respondents to the questionnaire on special education best practices showed a willingness to share the disciplinary expertise of the profession on 56.1% of the items in total. These results, however, were characterized by three distinct patterns of distribution. The special educators viewed many clusters of related items as appropriate for role release at all levels; some clusters as *in*appropriate at all levels; and some clusters as appropriate at some levels, but not at other levels. These three patterns were seen differentially across the four Professional Practice Themes and within the more detailed theme components.

The professional expertise the special educators were willing to share at *all* levels is summarized in Table 3. Support for role release at all levels occurred in all four Professional Practice Themes. In fact, the special educators met or exceeded criterion role release on all items, across all theme components in Professional Practice Themes II (Assessment and planning); III (Program Implementation), and IV (Program Administration). Within the first Professional Practice Theme (Disciplinary Content) the data on the theme component of the *science of human behavior* revealed high levels of role release for the clusters of related items describing the elements of the A-B-C paradigm, cues and prompts, and inclusion strategies. Other clusters of relat-

TABLE 3
Role Release at *All* Levels of Special Education Best Practices

Themes of Professional Practice	Theme Components	Content focuses on . . .	Questionnaire Item Numbers
I—Disciplinary Content	The Science of Human Behavior	Medical and physiological factors that influence human behavior	1 through 7
		The "A" in the behavioral paradigm(including modifications as appropriate)	8 through 13
		The "B" in the behavioral paradigm	14 through 19
		The "C" in the behavioral paradigm	20 through 25
		Positive reinforcement	26 through 37
		Cues and prompts	50 through 55
		Selection of settings	68 through 73
		Inclusion strategies	74 through 79
		Positive behavioral support	80 through 86
		Extinction, time-out, and response-cost	99 through 104
	The Partial Participation Principle	The Partial Participation Principle	122 through 127
II—Assessment and Planning	Plan and Conduct Assessment	Select assessment models; plan and conduct assessment	140 through 142
	Synthesize Assessment Results	Use of assessment results to select infused skills, functional activities, levels of participa-	143 through 147

TABLE 3—*Continued*

Themes of Professional Practice	Theme Components	Content focuses on . . .	Questionnaire Item Numbers
		tion and intervention methods; select evaluation methods referenced to participation in functional activities	
	Program Planning	Determine priority goals based on input of parents and all team members; establish a schedule that reflects both direct and indirect related services	148 through 150
III—Program Implementation	Classroom/ Community-Based Service Provision	Management of related services that are integrated physically and programmatically	151 through 153
	Home-School Partnership	Collaborative communication methods between home and school	154 through 155
IV—Program Administration	Ongoing Communication with School Administrators	Collaborative communication methods between team and school administrators	156 through 157

ed items revealed less consistent responses in support of role release with this theme component, and throughout the larger Professional Practice Theme. The clusters of related items that produced criterion level support for role release are summarized according to theme component and Professional Practice Themes in Table 3.

The clusters of related items the special educators chose to withhold within their discipline were found only within the first Professional Practice Theme (Disciplinary Content). One cluster of related items within the theme component of the *science of human behavior* was viewed as inappropriate for role release at any level. This cluster described the content of the *discrete trial format*, the foundation for systematic instruction in the framework of applied behavior analysis. Additionally two entire theme components within this Professional Practice Theme were viewed as inappropriate for role release at any level: 1) functional curriculum; and, 2) chronologically age-appropriate instructional materials. The professional expertise that was viewed by these special educators as inappropriate for role release is summarized in Table 4.

The third pattern of responses on this questionnaire was variability across levels of role release within a cluster of related items. Although this pattern occurred in only the first Professional Practice Theme (Disciplinary Content), other noteworthy and quite specific results occurred in all four Professional Practice Themes. What follows is a narrative description of specific results within Professional Practice Theme, organized according to theme component when relevant. In this detailed description, the narrative first focuses on the inconsistent pattern of role release across levels that occurred so frequently in the first Professional Practice Theme. Each cluster of related items in which this pattern occurred is described within the framework of the larger theme component of which these items were a part. A

TABLE 4
Lack of Special Education Role Release at Any Level

Themes of Professional Practice	Theme Components	Content Focuses On . . .	Questionnaire Item Numbers
I—Disciplinary Content	The Science of Human Behavior	Elements of the discrete trial format	38 through 43
	Functional Curriculum	The Individualized Curriculum Sequencing (ICS) Model	110 through 115
	Chronologically Age-Appropriate Instructional Materials	Chronologically Age-Appropriate Instructional Materials	134 through 139

summary of this pattern of responding, including the precise percentage of support for role release per item, accompanies this section in Table 5. The narrative then continues with brief descriptions of noteworthy results that were seen in each of the remaining three Professional Practice Themes as well.

Professional Practice Theme I—Disciplinary Content. This professional practice theme covered a broad range of theme components: the theory and practice of applied behavior analysis (Alberto & Troutman, 1986; Sulzer-Azaroff, & Mayer, 1991; Wolery, Bailey, & Sugai, 1988), activity-based curriculum, and the Partial Participation Principle (Baumgart, et al., 1982; Ferguson, & Baumgart, 1991). Although the overall percentage of willingness to share the discipline of special education was recorded on 56.1% of the questionnaire items, the percentage in Component I was slightly lower at 54.6%. Results specific to clusters of related items within theme components follows.

The Science of Human Behavior. This theme component totaled 109 items beginning with full descriptions of all three elements of the A-B-C paradigm; the use of positive reinforcement; the design, implementation, and evaluation of systematic instruction; prompt procedures; stages of learning; setting; strategies for inclusion; and concluding with strategies for positive behavioral support, as well as more traditional behavior management. The inconsistent pattern of role release was first seen in the cluster of related items regarding instructional design (i.e., shaping, backward and forward chaining, the total task approach to skill instruction). Within this cluster, general information, informational skills, and performance skills were viewed as content to be withheld by many respondents; whereas the problem-solving level of this content was seen as appropriate for role release by 82.3% of these special educators. The same pattern of responding (i.e., criterion level support for role release at the level of problem-solving only) was seen in the subsequent cluster of related items addressing the content of "stages of learning." However, a slightly different pattern was seen in the cluster of items on data collection techniques. In this cluster of related items, both performance skills and problem-solving skills were viewed as appropriate for role release, but not the levels of general information and informational skills.

Inconsistent willingness to share across levels was seen again on the clusters of items describing the content areas of differential reinforcement, negative reinforcement. and emergency procedures related to the management of crisis behaviors. Although visual examination of Table 5 reveals no completely consistent pattern across these three theme components, there seems

TABLE 5

Clusters of Related Items from Special Education Best Practices Revealing Inconsistencies in Role Release at Various Levels

Item Description by Content Focus	Level of Role Release	Percentage of Respondents Who Expressed a Willingness to Engage in Role Release
Instructional Design		
44. Knowledge of instructional design (e.g., shaping, chaining).	General information	64.6%
45. Recognition of instructional design in application.	Informational skill	64.6%
46. Design instruction.	Performance skill	70.5%
47. Implementation of instructional design.	Performance skill	70.5%
48. Evaluation of instructional design.	Problem-solving skill	82.3%
Stages of Learning		
56. Knowledge of the stages of learning (acquisition, fluency, etc).	General information	64.6%
57. Recognition of the stages of learning in application.	Informational skill	64.6%
58. Design instruction at the appropriate stage of learning.	Performance skill	70.5%
59. Implementation of instruction at the appropriate stage of learning.	Performance skill	70.5%
60. Evaluation of instruction at various stages of learning.	Problem-solving skill	76.4%
Data Collection		
62. Knowledge of data collec-	General information	70.5%

TABLE 5—*Continued*

Item Description by Content Focus	Level of Role Release	Percentage of Respondents Who Expressed a Willingness to Engage in Role Release
tion.		
63. Recognition of data collection in application.	Informational skill	70.5%
64. Design instruction incorporating data collection.	Performance skill	82.3%
65. Implementation of instruction incorporating data collection.	Performance skill	82.3%
66. Evaluation of the usefulness and practicality of data collection systems.	Problem-solving skill	82.3%
Differential Reinforcement		
87. Knowledge of differential reinforcement techniques.	General information	70.5%
88. Recognition of differential reinforcement in application.	Informational skill	82.3%
89. Design differential reinforcement techniques.	Performance skill	70.5%
90. Implementation of differential reinforcement techniques.	Performance skill	76.4%
91. Evaluation of the design/use of differential reinforcement techniques.	Problem-solving skill	70.5%
Negative Reinforcement		
93. Knowledge of negative reinforcement.	General information	82.3%
94. Recognition of negative reinforcement in applica-	Informational skill	82.3%

TABLE 5—*Continued*

Item Description by Content Focus	Level of Role Release	Percentage of Respondents Who Expressed a Willingness to Engage in Role Release
tion.		
95. Design negative reinforcement techniques.	Performance skill	70.5%
96. Implementation of negative reinforcement techniques.	Performance skill	70.5%
97. Evaluation of the design/use of negative reinforcement techniques.	Problem-solving skill	64.6%
Physical Restraint as an emergency procedure only.		
105. Knowledge of physical restraint.	General information	82.3%
106. Recognition of physical restraint.	Informational skill	76.4%
107. Design physical restraint.	Performance skill	70.5%
108. Implementation of physical restraint.	Performance skill	76.4%
Activity-based Curriculum		
116. Knowledge of activity-based curriculum (i.e., the major source of curriculum consists of the same activities as those engaged in by same age peers without disabilities).	General information	76.4%
117. Recognition of activity-based curriculum in application.	Informational skill	70.5%
118. Design activity-based cur-	Performance skill	70.5%

TABLE 5—*Continued*

Item Description by Content Focus	Level of Role Release	Percentage of Respondents Who Expressed a Willingness to Engage in Role Release
riculum.		
119. Implementation of activity-based curriculum.	Performance skill	64.6%
120. Evaluation of the design/use of activity-based curriculum.	Problem-solving skill	64.6%
Infused Skills		
128. Knowledge of infused skills (i.e., "core" skills or "essential" skills) and why instruction on these skills (e.g., visual fixation, auditory localization, simple manipulation, etc.) should be incorporated into an activity based curriculum.	General information	82.3%
129. Recognition of infused skills in application.	Informational skill	82.3%
130. Design instruction that incorporates infused skills.	Performance skill	64.6%
131. Implementation of instruction that incorporates infused skills.	Performance skill	76.4%
132. Evaluation of instruction that incorporates infused skills.	Problem-solving skill	70.5%

to be a tendency on the part of the special educators to withhold performance skills on these content areas, as well as problem-solving skills.

Functional Curriculum. The theme component of functional curriculum consisted of 12 items. Only one of the items in this section was seen as appropriate for sharing across disciplinary boundaries: activity-based curriculum at the level of general information. None of the other 11 items addressing additional levels of competence around activity-based approaches, or any level of role release related to curriculum skill sequences were seen as appropriate for sharing with fellow team members.

Infused Skills. The dimension of infused skills produced variable responses on the part of study participants. Both general information and the informational skill related to this content were viewed as appropriate content for role release, but neither the performance skill of designing instructional interactions that incorporate infused skills, or the problem-solving level were viewed in the same way.

Professional Practice Theme II—Assessment and Planning. This component was organized into three sections titled: a) plan and conduct assessment; b) synthesize assessment results; and, c) program planning. Each of the three sections contained between three and five items producing a total of 11 items in the component. All of the items were viewed as appropriate for role release with very high levels of agreement noted between participants. The range of items addressed the selection and use of multiple assessment models, as well as use of assessment results to select infused skills, determine level of participation, and select intervention methods.

Despite the fact that some of these items was viewed as *inappropriate* for role release when they were first encountered in the first Professional Practice Theme on Disciplinary Content, when this same content was described in the context of assessment and planning, very high levels of expressed willingness to engage in sharing across disciplinary boundaries occurred.

Professional Practice Theme III—Program Implementation. This component was very short, consisting of 5 items distributed across two sections: a) classroom/community based service provision; and, b) home-school partnership. All items were seen as appropriate for sharing by the study participants. These items included information on how to review individual performance data and direct revision of intervention strategies as appropriate, as well as information on how to direct ongoing communication between home and school. Other noteworthy items in this section that were seen as appropriate for role release included those specifically related to the *management* of service provision, including information regarding how to integrate related services physically (i.e., therapy services offered in the setting that serves as the context for other elements of the educational program) and programmatically (i.e., therapy services referenced to the learner's educational program).

Professional Practice Theme IV—Program Administration. The final component of the questionnaire on special education best practices consisted of only two items related to the topic of communication methods to be used with school administrators on matters of program implementation. There was agreement that information on this topic should be shared with all members of the team.

Physical And Occupational Therapy

A threshold of seven of nine (77.7%) respondents was designated as indicative of criterion level willingness to share the disciplinary expertise specified in a questionnaire item. Using this as a criterion, the respondents to the questionnaire on occupational and physical therapy showed a willingness to share the disciplinary expertise of their profession on 55.6% of the items. The data generated by the occupational and physical therapists, however, revealed somewhat different patterns of responses when compared to those generated by the special educators on their teams. Again, *some* clusters of related items were viewed as wholly appropriate for role release. This pattern of support for role release across levels was seen in all four Professional Practice Themes, but the support was much less consistent than that expressed by the special educators, particularly in the first Professional Practice Theme (Disciplinary Content). These data are summarized in Table 6.

There was only one section of the questionnaire that these therapists were *un*willing to share at any level. This set of responses occurred on the entire theme component of *plans and conducts assessment* within the second Professional Practice Theme (Assessment and Planning).

A third, very consistent pattern of responding occurred as well in these data. In the first Professional Practice Theme (Disciplinary Content), the therapists withheld their expertise at the level of *performance competency* across the majority of theme components. More specific results, organized according to each Professional Practice Theme, and the more detailed theme components when relevant, follow.

Professional Practice Theme I—Disciplinary Content. This section of the questionnaire covered a broad range of content areas; sensory factors related to posture and movement, muscle tone, posture and alignment, multiple aspects of movement, and materials/task adaptation. Although the

TABLE 6
Occupational and Physical Therapy Expertise Shared at *All* Levels

Themes of Professional Practice	Theme Components	Content Focuses on . . .	Questionnaire Item Numbers
I—Disciplinary Content	Sensory Factors Related to Posture and Movement	Importance of sensory stimuli in contributing (both negatively and positively) to normalized posture and movement	1 through 5
II—Assessment and Planning	Program Planning	Determine priority goals; establish a schedule that reflects both direct and indirect related services	60 through 62
III—Program Implementation	Direct Service Provision	Implementation of direct (i.e., "hands on") related services that are integrated physically and programmatically; monitor outcomes and revise direct service provision as indicated	63 through 65
	Indirect Service Provision	Implementation of indirect (i.e., consultation) related services that are integrated into	66 through 68

TABLE 6—*Continued*

Themes of Professional Practice	Theme Components	Content Focuses on ...	Questionnaire Item Numbers
		classroom and community routines; monitor outcomes and revise indirect service provision as indicated	
	Home-School Partnership	Collaborative communication methods between home and school	69 through 70
IV—Program Administration	Ongoing Communication with School Administrators	Collaborative communication methods between team and school administrators	71 through 72

overall percentage of willingness to share the disciplines of occupational and physical therapy was recorded on 55.6% of the questionnaire items, the percentage in the first Professional Practice Theme was somewhat higher at 59.6%.

This Professional Practice Theme consisted of 52 items organized into eight theme components. With the exception of the first theme component *(Sensory Factors Related to Posture and Movement)*, analysis of the remaining seven theme components revealed the same pattern of willingness (and unwillingness) to support role release. Each theme component began with items at the levels of general information and informational skills. The items at these levels were characterized by a strong willingness on the part of the therapists to share expertise across disciplinary boundaries. Analysis reveals 88.9% to 100% support for role release at these two levels. Items at the level of *performance competency* within these theme components, however, resulted in very low levels of support for role release. Specifically those items that contained the words *design or implement* resulted in a range of role release from 0% to 66.6%; with a median percentile of 33.3% support for role release. Conversely, those items at the highest level of role release (problem-solving), were again viewed as highly appropriate for sharing across disciplinary boundaries. The range of agreement to share at the problem-solving level was 77.7 to 100% with a median percentage of 88.8%.

In addition to this consistent pattern of more and less willingness to share expertise related to *level* of the items, these therapists added new items to theme components with much greater frequency than did their team members from special education. Specific results for this Professional Practice Theme related to each theme component are described more fully below.

Sensory Factors Related to Posture and Movement. This theme component was the only set of related items within this Professional Practice Theme that resulted in criterion level support for role release at all levels. The content of this theme component also prompted these respondents to generate three additional items. The therapists identified tactile defensiveness as an important element to be added, as well as special handling approaches that they viewed as helpful in minimizing this phenomenon.

Muscle Tone. There was reluctance on the part of respondents to share methods of therapeutic positioning to normalize tone, a performance skill in this theme component. Again content additions were made, including expressions of willingness to share positioning equipment, as well as ideas for activities to capitalize on normalized muscle tone.

Range of Motion. The three performance skills in this theme component were viewed as content to be withheld within these disciplines. Interestingly, none of these respondents found it acceptable to teach their team members how to implement passive range of motion, a skill that is released frequently to people who are not therapists. A possible insight into the strong position taken in regard to this item was found in the comment section. These respondents found the term "Implement therapeutic techniques" to be problematic. They expressed a willingness to share therapeutic techniques only in those situations that permitted close collaboration.

Muscle Strength and Endurance. The questionnaire items in this theme component that included the terms "design" or "implement" were viewed as inappropriate for role release; whereas all respondents expressed a willingness to share at the levels of general information, informational skills, and problem-solving skills. An additional item contributed by these respondents was their willingness to teach fellow team members how to recognize when a child may benefit from a change in position, such as sitting in a static position in a wheelchair for a prolonged period of time.

Posture/Postural Alignment. Again only those questionnaire items that included the terms "design" or "implement" were viewed as inappropriate for release across disciplinary boundaries. The respondents generated additional items to this content focus including appropriate positions for eating and feeding, as well as how to implement feeding techniques.

Balance and Automatic Movement—Functional Use of Movement. These two theme components both addressed movement. The responses in both sections mirrored the previous two regarding the willingness of these respondents to share general information, informational skills, and problem-solving skills; while withholding the performance skills related to task design and implementation.

Material and Task Adaptation. The final section in this Professional Practice Theme revealed a similar pattern of responses to those described earlier. In this theme component, however, a majority of respondents were willing to share their disciplinary expertise regarding task *implementation* that included "the appropriate use of adaptive training aids to enhance an individual's performance of a functional activity." These same respondents did, however, withhold support for role release on the related performance competency in which the *design* function of material and task adaptation was described.

Professional Practice Theme II—Plans and Conducts Assessment. As described earlier for the questionnaire on special education best practices, this Professional Practice Theme was divided into three sections. For this questionnaire, however, there were ten items distributed across three theme components: a) plans and conducts assessment; b) synthesizes assessment results; and, c) program planning. Unlike the respondents from the discipline of special education, the occupational and physical therapists were willing to share only three of the ten items; one in the cluster of items related to synthesizing assessment results, and two of the three items related to program planning. There was no willingness to share information related to planning and conducting assessment. An additional comment was made after this theme component: "Following discipline-specific assessment, results are shared with other disciplines so that we are all working toward common goals."

An interesting finding in this section pertained to an item that asked whether it was appropriate for therapists to share information on how to measure progress referenced to the performance of functional skills (i.e., educational criteria), as opposed to clinical criteria that are more medical in nature. Six of the nine respondents believed in the appropriateness of sharing this content, one was unwilling to do so, and two were unsure.

Professional Practice Theme III—Program Implementation. This Professional Practice Theme was somewhat longer than its parallel construction in the questionnaire on special education. This Professional Practice Theme consisted of eight items distributed across three theme components: a) direct service provision; b) indirect service provision, and, c) home-school partnership. *All* items were seen as appropriate for role release including those related to how services may be physically and programmatically integrated, as well as strategies for collaborative review of performance data and revision of strategies as indicated by the data.

Professional Practice Theme IV—Program Administration. The final Professional Practice Theme consisted of only two items, both related to ongoing communication with school administrators. As also seen in the responses made by the special educators, there was criterion level support for role release in this content area.

DISCUSSION

The two elements of adult team effectiveness that may pertain to the present study are: 1) interdependence; and, 2) individual accountability for personal responsibilities. These data may be interpreted in light of both of these elements.

Interdependence. Although true positive interdependence implies the recognition among team members that they are *all* responsible for the educational and related service outcomes of *all* students; the views of these team members relative to their roles in sharing knowledge and skills related to planning, implementation, and evaluation of these services varied. Thousand and Villa (1990) suggested that positive interdependence is facilitated by having each team member answer a series of questions for themselves. The question that seems most pertinent to these data is—*How do team members arrange to share their expertise?* There appears to be an assumption underlying this question that expertise *will* be shared. The data reported here suggest that neither special educators nor physical and occupational therapists expressed unconditional willingness to share the knowledge and skills of their respective disciplines with fellow team members. Nonetheless, certain patterns of role release emerged, both within and across disciplines, that are noteworthy.

Special Education. A majority of special educators expressed a desire to withhold complete elements of expertise within their discipline. These areas included the "discrete trial format" that serves as the foundation for systematic instruction; one cluster of related items within the theme component of functional curriculum (the Individualized Curriculum Sequencing [ICS] Model); and the last cluster of related items in this theme component—the use of chronologically age-appropriate instructional materials. In addition to these content areas, there was inconsistent willingness to share expertise (at one or more levels) across multiple theme components describing the disciplinary content of special education. Although support for role release was inconsistent (i.e., was not clearly linked to a particular *level* of role release), it may be suggested that the reluctance to engage in role release was linked most strongly to those theme components that may be considered essential to the identity of special education as a discipline. Lack of support for role release was seen in the theme components related to curriculum and instructional design. Clearly, these respondents viewed this content in a framework that may be described as discipline-referenced, inappropriate for role release to colleagues from other disciplines.

Within the content area of applied behavior analysis, there was virtually no willingness to share, at any level, the traditional behavior management techniques of differential reinforcement, negative reinforcement, and emergency procedures for crisis situations. However, technically punishment procedures, extinction, time-out-from positive-reinforcement, and response-cost were not viewed in the same way. Although a possible interpretation for these results may be that the special educators were unwilling to share behavior management techniques that are punitive or severe, this is not supported by further analysis of the data. Differential reinforcement is not a punishment technique and is much less severe than time-out-from-positive-reinforcement in terms of its intended consequences (i.e., building a response repertoire through the planned introduction and withholding of positive reinforcement, as opposed to behavior reduction). An alternative explanation may be the perceived ease with which extinction, time-out-from-positive-reinforcement, and response-cost can be implemented. These procedures are quite straightforward, unlike the correct use of differential reinforcement, which requires a sophisticated understanding of stimulus control and excellent observation skills to be used effectively.

Occupational and Physical Therapy. These data revealed some differences from those expressed by the special educators on the same teams. One consistent pattern was the unwillingness of these therapists to share their expertise at the level of *performance* competency. Specifically, the majority of these respondents were unwilling to surrender disciplinary expertise related to *designing* and *implementing* tasks in which therapeutic techniques were embedded. The data generated on this questionnaire also reveal that these therapists were willing to share both general and specific information, as well as the framework for evaluation of therapeutic interventions, with their special education colleagues. These data seem to support the position taken by Woodruff and McGonigel (1988), who suggested that the process of role release (within their model of role extension) proves to be the most difficult step for team members to implement.

These therapists were also unwilling to share their framework for planning and conducting assessment, although they expressed strong willingness to share their assessment results in ways to facilitate the development of common goals.

Individual Accountability. Another framework for interpretation of these data relates to the fifth condition described as central to the effectiveness of adult teams: individual accountability. In a collaborative team, members monitor one another's performance, set limits on one another's behavior, and take responsibility for helping colleagues to improve. Individual accountability in the context of a group has the potential for increasing accountability for the team as a whole. It may be that the longitudinal opportunities these team members had to scrutinize each other's behavior resulted in their unwillingness to share selected elements of their disciplinary expertise. They may have used their professional judgement to determine which elements of their professions they felt comfortable sharing, and then met the standard of individual accountability by withholding those elements they feared may not have been implemented well by their team members from other disciplines.

Conclusions. These data are encouraging for a number of reasons. Both groups of professionals were willing to share significant elements of their respective disciplines with one another. Although certain elements of professional expertise were withheld in both groups (e.g., instructional and curricular design by special educators; performance competencies for multiple aspects of disciplinary content in physical and occupational therapy); the collective commitment to role release demonstrated by these professionals is noteworthy. Support for role release was expressed on over half of the elements of disciplinary expertise described on these questionnaires (56.1% for special educators; 55.6% for physical and occupational therapist). It may be particularly encouraging that the problem-solving level of role release produced such high levels of support in both groups. The willingness to engage in collaborative problem-solving communicates a high level of trust between these team members—an essential element of shared responsibility *and* shared accountability (Friend & Cook, 1992; Givner & Haager, 1995).

Conversely, these data are somewhat discouraging. These respondents were veteran team members. With the exception of two special educators who had only two years of experience in one of the collaborating agencies, each of the other team members had served children and youth with disabilities for a minimum of four years. It may be expected that this period of time would have produced even greater levels of shared knowledge and expertise among these team members. Although their support of role release, particularly at the level of problem-solving, was noteworthy, some authorities view collaboration as *more* than problem solving, but instead as the foundation for good service provision (Johnson & Pugach, 1996). These data do not permit a judgement to be made as to whether the degree of support for role release expressed by members of these teams was sufficient for "good service provision."

Physical and occupational therapists rarely enter employment in school settings prepared for the concept of sharing roles with team members representing other disciplines. This absence of teaming skills can develop into feelings of frustration for many therapists in school settings. Both initially, and over a period of time, many school-based therapists are able to understand their role as related service providers (language used in the Individuals with Disabilities Education Act [IDEA]), whereby they will "assist a child with a disability to benefit from special education." (34 C.F.R. section 300.24). In many ways, the IDEA, federal legislation entitling children with disabilities to receive special education and related services, intends for schoolbased therapists to work with other professionals in providing services in schools (Rapport, 1995)

Additionally, Thousand, Villa, Paolucci-Whitcomb, and Nevin (1996) have articulated that specialists and generalists are more likely to acquire one another's skills (i.e., to share knowledge and expertise) as they interact over time. Although prolonged interaction may be a necessary condition for role release to occur, it was insufficient for these professionals to fully meet the challenges of role release. For the most part, these team members had interacted with one another for *extended* periods of time (up to 13 years in one team) yet had not fully acquired one another's skills.

Summary. It has been suggested that the physical and conceptual isolation in which many professionals with specialized expertise have operated must end (Spodek, 1982). It is hoped that these preliminary data on the extent of support for role release in teams who serve children and youth with severe and multiple disabilities will facilitate an examination of *which* elements of a profession should be shared to create quality service provision. These data suggest that the dual conditions of effectiveness that require both positive interdependence *and* individual accountability are best fulfilled at the levels of role release documented in this study. It is hoped as well that these data will contribute to the ongoing dialogue regarding *how* to meet the challenge of effective teamwork; for it is clear that all professionals who serve students with disabilities *must* increase their communication and knowledge of each other's expertise to fulfill the promise of our disciplines.

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REVIEW OF RESEARCH AND CONCEPTUAL LITERATURE ON THE USE OF BOTOX WITH INDIVIDUALS WITH CEREBRAL PALSY AND RELATED SPASTIC DISORDERS

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ABSTRACT

The purpose of this article is to review the literature related to an experimental therapy for students with cerebral palsy and related spastic disorders, specifically to inform parents and teachers of this drug therapy. Botulinum Toxin Type A (Botox) has recently been administered to a sizeable number of students with cerebral palsy and related spastic disorders in clinical settings to reduce dystonic movements.

Botox, a poison, was injected in extremely small amounts into affected muscles. Although complex, the end result is that Botox blocks nerve impulses to relax the muscle and relieve the spasm. The first clinical trials are encouraging for individuals with spastic cerebral palsy. A review of the literature on Botox therapy, both medical and otherwise, was conducted.

If the treatment remains as promising as the first trials indicate, a number of students with cerebral palsy and related spastic disorders may participate to a greater extent in full inclusion classes as opposed to remaining in self-contained classroom settings. Side effects and other related issues are discussed

Cerebral palsy, originally called "Little's Disease" and later "spastic paralysis," has been a perplexing problem for both educators and physicians for quite some time (Hill, 1999). Most students with cerebral palsy have sustained brain damage to the pyramidal or extra-pyramidal systems in the cerebrum during the prenatal, perinatal, and to a lesser extent the postnatal periods (Nelson & Ellenberg, 1986). Past beliefs have blamed anoxia or asphyxia as the primary causes for the cerebral damage. However, Russman (1992) indicated that asphyxia was not a common cause of cerebral palsy. Today, accepted causes include: prenatal anoxia, toxemia, maternal bleeding, placental insufficiency, and multiple births (Heller, Alberto, Forney, & Schwartzman, 1996). The number of cerebral palsy students is approximately 1.9 per one thousand births (Lagergren, 1981). With the increase in the survival of low birth weight infants, and at risk children, the incidence of cerebral palsy has risen (Nicholson & Alberman, 1992).

At the heart of cerebral palsy is a generalized incoordination and/or involuntary movements which may range from slight to severe (Bigge, 1991). In the past, treatment consisted of extensive physical therapy, surgery to release overly tight tendons, heel cord lengthening, and bracing. A radical new surgical procedure was developed that selectively severs sensory nerve fibers in order to relieve spasticity. This surgical procedure is referred to as selective dorsal rhizotomy. Rhizotomy is the clipping of specific nerve roots to de-energize specific muscle groups (Berman, Vaughan, & Peacock, 1990). Occasional neurosurgery on a specific lobe of the cerebrum was performed primarily on a trial or experimental basis. However, such practice has always been considered to be an extreme measure. Drugs such as Valium, Klonapin, Lioresal, and other muscle relaxants and anticholinergic drugs also have been prescribed (Hill, 1999; Jankovic & Brin, 1991). These treatments which are still used, while helpful, do little to improve the student's overall coordination and ability to perform various life tasks.

The purpose of this article is to review the literature related to students with cerebral palsy and other spastic disorders utilizing an experimental drug therapy called Botox. Botulinum Toxin Type A, from which Botox is produced, has recently been administered to a sizeable number of students with cerebral palsy and related spastic disorders in clinical settings to reduce spastic and associated dystonic movements. Botox, however, is still in the experimental stages (Zelnik, Giladi, Goikhman, Keren, Moris, & Honigman, 1997).

BOTULISM

Botulism has been recognized by physicians since the 18th Century; however, its correlation to food poisoning was not discovered until 1897. Botulinum is a neurotoxin produced by the gram positive bacterium Clostridium Botulinum bacteria. There are eight serologically distinct toxins of which Type A is the most widely studied (Jankovic & Brin, 1991). Outbreaks of botulism occur when people ingest foods contaminated with the neurotoxin. In these cases, the bacteria produce large amounts of toxin that lead to potentially serious results. Botulinum toxin Type A is by far the best understood biological toxin. The toxin produces paralysis by blocking the presynaptic release of the neurotransmitter acetylcholine at the neuromuscular junction (Lagueny & Burbaud, 1996). As a result, contraction of skeletal muscle fibers is prevented. Botulinum intoxicated muscles react almost identically to surgically denervated muscles (Jankvoic & Brin. 1991). Muscle paralysis is dose-dependent and reversible.

BOTOX THERAPY

Botox was introduced as a safe and effective treatment for strabismus and other disorders of the extraocular muscles in the early 1980s. Approved by the U.S. Food and Drug Administration for use in the treatment of strabismus, blepharospasm, and seventh cranial nerve disorder, botulinum toxin has also been shown to be effective in a wide range of disorders associated with involuntary muscle contraction and spasm (Wheeler, 1997). The toxin is diluted to less than one-tenth of the amount that would cause harm and, unlike food poisoning, it does not travel throughout the body. Instead, it is localized to a specific muscle or muscle group. Botox is administered in units, much the same as insulin. One unit (1 U) of botulinum toxin is the amount that kills 50 percent of a group of 18 to 20 female Swiss-Webster mice (Jankovic & Brin, 1991). The pharmaceutical company, Allergan, holds the patent and produces the drug today.

Only lately has Botox been explored for students with various types of neuromuscular disorders including cerebral palsy. The specific injection sites are selected through the guidance of an electromyography (EMG) study (Hesse, Lucke, Malezic, Bertelt, Friedrich, Gregoric & Mauritz, 1994). Muscles can clearly be identified as contracting normally or abnormally from a stretched induced EMG study. Once the muscle or group of muscles are identified as the cause for the abnormal movement, Botox can be injected with precise accuracy.

OUTCOMES

The use of Botox on students with spasticity may eliminate the necessity of surgery or rhizotomy. The use of rhizotomy is a very tenuous type of neurosurgical procedure, with varying outcomes. Botox can be a viable substitute, with little to no associated permanent damage. An example is with spastic cerebral palsy students who have extremely tight heel cords, preventing them from having a normal gait. By injecting Botox into the overly tight muscle, a normal or near normal gait may be obtained. If complete correction cannot be obtained, Botox can be beneficial in conjunction with bracing to correct or improve various deformities. When a patient responds well to Botox and his or her spasticity is reduced, physical therapy can be significantly more effective, thus increasing the range of motion and improving ambulation. The positive effects of Botox are generally observable in three to five days. In addition, Botox has been studied for treating a variety of conditions involving inappropriate muscle activity. When injected into specific sites in selected muscles, Botox has been found useful in treating muscle spasms affecting vision (strabismus and blepharospasm). It has been found to be effective in treating long term spasticity in neck muscles as well as in diminishing spasticity in the throat muscles affecting speech (dysphonia). A number of individuals with these disorders who received a regimen of Botox have been followed for several years, notably by Dr. Stuart Yablon at the Methodist Rehabilitation Center in Jackson, Mississippi, Dr. Nester Galvez at the Florida Cleveland Clinic in Ft. Lauderdale, Florida, and others. Few, if any, reports of adverse side effects have been reported. Any difficulties reported appear to be transient and of very short duration. The use of Botox has been approved by the U.S. Government Food and Drug Administration.

SIDE EFFECTS

The side effects of Botox appear to be extremely minor. The current *Physicians Desk Reference* (Medical Economics Company, Inc., 1998) restricts its findings of adverse reaction to ocular treatments only. In ocular treatments, seven cases of diffuse skin rash and two cases of local swelling of the eyelid skin were reported. However, several investigators have included side effects in their studies of the use of Botox with spasticity and other applications. In its use with various age groups to counter the effect of spasticity and other disorders, Botox has been found to have no significant side effects (e.g. Bushara, Park, Jones, & Schutta, 1996; Fiorini, Corti, Valero, Bai, & Boerr, 1996; Koman, Money, Smith, Goodman, & Mulvaney, 1993; Laskawi, Drobik, & Schonebeck, 1998; Pribitikin, Greco, Goode, & Keane, 1997). It should be noted, however, that Wong (1998) found that while the use of Botox with children with spasticity produced no untoward side effects, there was some mild, transient pain associated with the injection site. Finally, Botox should not be administered to pregnant or nursing women (Dystonia Medical Research Foundation, 1994).

RESEARCH FINDINGS

The following are recent findings for the use of Botox with individuals with cerebral palsy and related spastic disorders:

- Hesse et al. (1994) found that Botox caused a definite reduction of planter reflex spasticity in 10 of 12 patients, ranging in age from 30 to 59 years, two weeks after the injection as assessed by the Ashworth Scale. Gait showed a statistically significant improvement ($p < 0.01$) in velocity, stride length, and stance symmetry. Also, painful positions, such as toe clawing, were reduced.
- Dunne, Heye, and Dunne (1995) studied the effects of Botox with 40 individuals with chronic limb spasticity, ranging in age from 12–42 years. The investigators found that 34 of 40 individuals (85%) derived worthwhile benefit, with improved limb posture and increased range of passive motion using the Ashworth spasticity and spasm frequency scale. Pain reduction occurred in 28 of 31 individuals with pain.
- Jankovic and Brin (1991) in a study with nine adult patients found that individuals with severe motor dysfunction due to abnormally increased muscle tone, such as spasticity, may be ameliorated by treatment with Botox.
- Laguny and Burbaud (1996) reviewed separate cases of the application of Botox to patients ages 12–70 years and found that Botox, with regard to spasticity associated with cerebral palsy, is a promising treatment requiring a multidisciplinary approach. The investigators further found that Botox injections lead to effective reduction of muscle hyperactivity with very minor side effects.
- Pascual-Pascual, Sanchez-de-Muniain, Roche, and Pascual-Castroviego (1997) found that in treating 39 cases of spastic and/or dystonia cerebral palsy, spasticity was significantly reduced after treatment. It went down two or more grades on the Ashworth Scale. Foot position in walking improved in two-thirds of the cases, knee flexion and hip hyperadduction were reduced up to 60 percent. The investigators concluded, "Botox is

highly effective in the treatment of CP, and if associated with physiotherapy long and even permanent effects can be achieved" (p. 145).

- Grazko, Polo, and Jabbari (1995) investigated the use of Botox with 12 individuals with spasticity and 8 individuals with rigidity, ages 12–81 years. According to the Ashworth Scale for spasticity, Botox reduced the tone in all 12 spastic individuals significantly, improved functionality in eight of the 12 individuals, and alleviated painful spasms in the five individuals with painful spasms. In the rigidity group, muscle tone was decreased in seven of eight individuals, functionality improved in four of seven, and joint pain decreased in four of five. "We conclude that botulinum toxin A (Botox) is effective against the disabling effects of spasticity and rigidity" (p. 45).
- Sampaio, Ferreira, Crespo, and Castro-Caldas (1997) investigated the use of Botox on 19 patients ranging in age from 26–72 years. Using the Ashworth Scale and Frendchay arm test, the investigators found that joint mobility and spasticity improved significantly ($p < 0.01$). The peak effect was attained one month after treatment, but clear decreases in scores (improvement) were apparent after the first week. The researchers concluded Botox has a clear anti-spastic effect.
- Thompson, Baker, Cosgrove, Corry, and Graham (1998) investigated the uses of Botox with ten children with tighter than normal hamstrings leading to a crouched gait. The investigators reported that knee flexion improved 15.6 degrees and patients with crouched gaits produced significant, repeatable, muscle lengthening and improved ambulatory function with Botox treatments.
- Using a case study method, Mall, Heinen, Linder, Philipsen, and Korinthenberg (1997) investigated the use of Botox with three children, ages 13, 15, and 16 years. The three patients with spastic cerebral palsy manifested various associated disorders relating to their spasticity. Parameters were assessed using the modified Ashworth Scale and joint mobility (range of motion). Patient 1 was affected with a shoulder luxation caused by muscular hyperactivity causing painful bending of the arm toward the back. During the night the patient awoke 2–4 times. Following the Botox treatment the patient's arm was not bent toward the back, allowing uninterrupted sleep for the first time in 12 years. Other life skills also significantly improved. Patient 2 manifested a flexion contracture of the left hand and a poor gait. Injection of Botox resulted in decreased muscular hyperactivity and increased ability to extend the whole hand. Also, this patient had a striking improvement in her mobility. Patient 3 manifested spastic diplegia with pes equinus and had to be

supported for standing and walking. Two weeks after being injected with Botox, the patient was able to walk unassisted for 50 meters for the first time in her life. The investigators concluded that Botox should be considered as part of a multidisciplinary treatment concept, since reduction of the disability may well have positive impacts on daily living activities.

- Wong (1998) investigated the use of Botox on 17 children with spastic cerebral palsy undergoing physiotherapy for ambulation. The investigator found all children experienced decreased spasticity scores within 72 hours. Three nonambulatory children became ambulatory with assistance and five children with assisted ambulation became more independently ambulatory. Also, the functional status of rising from the sitting position demonstrated improvement. This study revealed that Botox is useful as an adjunctive therapy in ameliorating spasticity in children with cerebral palsy, especially when initiated at young ages.
- Arens, Leary, and Goldschmidt (1997) investigated Botox as a therapeutic agent for posturing with spastic and dystonic forms of cerebral palsy in fifteen children (five with spasticity, five with dystonia, and five with a mixed picture). The investigators concluded that Botox is effective for better posturing of selected children with spastic and dystonic forms of cerebral palsy. Improvement is not permanent, but injections can be repeated, typically every six months.
- Sanchez-Carpintero and Narbona (1997) investigated the range of motion in 27 children with spasticity (10 with hemiplegia and 17 with diplegia). The hamstrings, triceps, and posterior tibialis were injected with Botox. Increases in the range of motion as measured by the PRS increased as follows: adductor angle 66%, knee angle 40%, and ankle angle 52%. The investigators highly suggest using Botox with stretching casts to increase range of motion in young children.
- Zelnik, Galadi, Goikhman, Keren, Moris, and Honigman (1997) investigated the effectiveness of Botox with 14 children with cerebral palsy with contracture of the gastrocnemius-soleus muscles (outside calf muscles). A combined functional score given by physicians, therapists, and parents showed a marked improvement in 6 patients (42.9%), a mild improvement in 3 patients (21.4%) and no improvements in 4 patients (35.7%).
- Koman, Mooney, Smith, Goodman, and Mulvaney (1993) investigated the effects of Botox in 27 young children with cerebral palsy who had dynamic deformities unresponsive to other treatment, except for complicated surgery. The investigators concluded that Botox injections may

allow delay of surgical procedures until the child is older and at less risk of complications, including the need for repeated surgical procedures.

- Palmer, Horn, and Harmon (1998) investigated the use of Botox in a single subject design. The case was a 19 year old male with significant flexion deformity and hypertonicity of the left wrist and hand. Ashworth scores revealed a significant reduction in tone and clonus of the sites injected with Botox. The investigators concluded that Botox is a useful adjunct in managing hand spasticity.

SUMMARY

In summarizing the advantages and disadvantages of Botox, the following appear to be most frequently mentioned:

Advantages:

- Administered by injection as an out-patient (office visit);
- Has had few minor adverse effects in thousands of injections;
- Leaves no surgical scar;
- No immobilization is required;
- Can be injected into even a single muscle; and
- Can dramatically improve the quality of life for many students with cerebral palsy.

Disadvantages:

- Cost of the drug is high; $400.00 per vial plus the cost of injection (can total $1,000 per treatment);
- Toxin antibodies may be built, rendering the drug ineffective;
- Injections must be repeated every three to six months;
- Some insurance companies do not pay for continuing Botox treatments; and
- Should not be utilized with pregnant or nursing women (Dystonia Medical Research Foundation, 1994).

DISCUSSION

As can be seen from the above, Botox appears to be a promising alternative for students with cerebral palsy and related spastic disorders. The advantages of Botox appear to outweigh the disadvantages. Because the benefits or nonbenefits of Botox are noticeable and measurable within three to five days, and the side effects appear to be temporary and reversible, some parents of students with cerebral palsy might consider Botox on a trial basis, upon appropriate medical advice.

In conclusion, Botox certainly is not a panacea nor a cure-all for the condition of cerebral palsy and related spastic disorders. However, in selected individuals, the results have produced improvements that have allowed students to engage in life activities that would have otherwise been denied them. Botox is more effective for the spastic form of cerebral palsy and less effective or not effective with the mixed or ataxic types (Arens, et al. 1997). The United Cerebral Palsy Association (UCPA) can direct parents to medical centers or neurologists that utilize Botox treatments. For further information, see United Cerebral Palsy Association website: http://www.ucpa.org/html/research/botox.html.

Although the initial studies with Botox look promising for students with spastic disorders, further research still needs to be conducted. For example, a longitudinal study could help determine the long-term effects of Botox therapy in terms of functional improvement and overall quality of life.

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THE EDUCATOR'S GUIDE TO FEEDING CHILDREN WITH DISABILITIES

Dianne Koontz and Suzanne McKeever Murphy
Paul H. Brookes Publishing Co.
$34.95, 256 pages, 1999

REVIEW

Eating—it is more than just "refueling"—is one of the most social, pleasurable, and motivating activities in our culture. For children with disabilities who have complex feeding needs, the feeding process requires thought and planning to be successful and enjoyable. Many educators who care for children with complex feeding needs may find that making mealtime enjoyable for their students while meeting physical, social, and educational demands is an overwhelming task. Dianne Koontz Lowman and Suzanne McKeever Murphy have provided a very practical guide for educators who feed children with disabilities who have feeding problems. While drawing on the expertise of several other professionals as well as their own, Lowman and Murphy present a holistic, student-centered approach to feeding that is not overwhelming to use.

Each chapter provides succinct definitions of the disabilities or physical processes to be discussed, with drawings or readable tables to clarify specific information when needed. Eleven of the twelve chapters include brief vignettes of children with feeding problems, followed by practice exercises with which the reader can apply ideas from the chapter.

Students described in the vignettes represent a diverse range of disability categories, ages, and individual needs and activities, which is illustrative of the individualized situations that educators of students with disabilities encounter. All suggested plans for intervention throughout this book incorporate a team approach, recommending collaboration between students' families, teachers, therapists, and other caregivers, promoting a holistic approach to feeding.

Chapter 1 focuses on the reasons why educators should learn feeding skills, and names the components of an educational planning team, (including the role of the educator on the team), followed by a description of each team member's general perspective and primary concerns about feeding. The vignette in this chapter illustrates some frustrations educators may experience with feeding a child with complex needs, ending with practice questions which require the reader to reflect on her/his own perspectives on feeding. The chapter is followed by an appendix with specific questions to guide the reader through the process of developing a holistic feeding plan.

Collaboration and teams is the theme of Chapter 2, which includes stages of the team process, team models, the role of the family in the team, and communication strategies to increase team effectiveness. The role of the entire team in developing a feeding plan is discussed and a vignette/exercise involving conflict within a team is presented. An appendix following the chapter lists resources that provide more information about teaming and collaboration.

Chapters 3, 4, and 6 inform the reader about normal and abnormal development of oral and respiratory structures and about physical and sensory issues to consider for feeding. Each chapter begins with general information about a body system and its normal development, contrasted with abnormalities that can occur in the system and how the abnormalities relate to feeding. Suggestions for assessment and intervention follow. A discussion on sensory integration in Chapter 6 may raise questions for some readers because the components and effects of sensory integration are difficult to document. The information in these chapters is presented in a clear, concrete fashion that is accessible for readers who do not have a background in anatomy. These chapters provide information that may not be background knowledge for teachers, but is essential for a full understanding of students' feeding needs.

In Chapters 5, 7, 8, and 9, specific strategies and adaptations to facilitate positive feeding experiences are discussed. The influence of posture during feeding and other activities, with suggested equipment, strategies, and a checklist for observing postural alignment are presented in Chapter 5, followed by an appendix listing adaptations and strategies for positioning in sitting. Chapter 7 provides an outstanding, child-centered view of the role of communication in feeding, including a discussion of the relationship of speech development to feeding, empowerment and socialization opportunities for the child, common communication problems during elements of the feeding process, and specific ideas for intervention. Chapter 8 suggests ways to adapt equipment to encourage independent eating while attempting to keep adaptations unobtrusive. "High-" and "low-tech" adaptations are suggested, with pictures of equipment and criteria for team decisions about when to adapt. Behavior strategies for feeding are covered in Chapter 9, emphasizing the view of behavior as communication. Positive models for behavioral support and analysis are discussed, with applications to the feeding context.

Chapters 10 and 11 describe the feeding needs and possible interventions for persons who have complex health care needs (with issues such as tube feeding and aspiration) and sensory disabilities (hearing and visual impairment and deafblindness). An appendix listing resources to help include children with complex health care needs is also included. The final chapter of the book draws from the information presented in prior chapters to guide the reader through the process of developing an overall feeding plan.

This practical, informative guide concludes with three more appendices, all of which are useful resources and can be reproduced for use in service provision with students who have disabilities. Appendix A is a holistic feeding observation form with questions about observable influences on feeding in all of the areas covered earlier in the book. The completed form provides a useful tool for outlining a feeding plan. Appendix B is a health services plan form that can be used to gather valuable health care information for students with complex health care needs, and Appendix C is a postural alignment checklist which is a concrete way for nonexperts to observe and evaluate postural alignment. A glossary of terms specific to the scope of the book is also included after the 12 chapters.

The Educator's Guide to Feeding Children with Disabilities is a valuable, very practical resource for educators of students with disabilities. Its presentation of the many factors that influence the experience of eating helps the reader to realize the importance of eating for students' quality of life and learning opportunities. The issues raised in the book apply to every student with physical or sensory disabilities (not just students with severe physical disabilities, as it would be easy generally to assume). Clear, brief information presented in a logical fashion, along with practical observation tools, forms, and suggestions for development of a successful feeding plan make the book a valuable guide for the busy educator who must respond to many diverse demands. These worthy characteristics are wisely coupled with Lowman and Murphy's recommendation that feeding and positioning decisions be made in a team context which includes consultation with an occupational and physical therapist.

Eating, which is so central to our lives, is worth careful consideration for students with disabilities Lowman and Murphy's book is an excellent, comprehensive guide to help educators provide the best possible feeding experiences for their students.

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COLLABORATIVE TEAMS FOR STUDENTS *WITH SEVERE DISABILITIES:* INTEGRATING THERAPY AND EDUCATIONAL SERVICES

Beverly Rainforth and Jennifer York-Barr
Paul H. Brookes
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REVIEW

Creating effective instructional programs for students with severe disabilities within inclusionary settings is challenging for educators, parents, administrators and related service providers. The logistical, programmatic, scheduling and communication variables that impact service provision are complicated and pervasive. It takes a comprehensive, in-depth guide, grounded in principles and supported with empirical evidence, to be of significant help to practitioners. Beverly Rainforth and Jennifer York have provided such a guide. One that is not only useful for related service providers, but special and general educators as well. This welcomed second edition provides updates in terms of "best practices" and new legal requirements along with longstanding observations regarding what "works" in the field. It combines academic, theoretical, clinical and practical information into one well-organized, readable textbook.

The book is organized into three main sections: (a) Philosophical, legal and programmatic foundations; (b) Designing Individualized Education Programs, and (c) Implementation Strategies and Issues. The first three chapters intelligibly lay out the framework and rationale for successful inclusionary programs for students with severe disabilities. One of the strengths of the book is that the authors clearly define terms and concepts that are crucial to effective inclusionary practices. For instance, the concept of "severe disabilities" is defined in a way that does not focus solely on deficits, but in relationship to the supports needed. In addition, there is a clear distinction made among terms such as mainstreaming, integration and inclusion. Characteristics of inclusive environments include not only structures in place, but also what happens in those environments. In addition, the positive benefits of integrated therapy, collaborative teamwork and family partnerships are laid out for practitioners. One of the strongest sections thoroughly describes why context is such an important principle needed to enhance learning, and how it contributes to acquisition, retention, synthesis and generalization. Anyone interested in how people learn would do well to read this section.

Throughout this first section the sociological rationale for integrated therapy is carefully detailed. A second principle, the importance of context in learning of "educational relevance" provides the groundwork for teaching in natural environments. Helpful examples of how these principles can be implemented within schools are provided. Chapter 1 also articulates why and how to focus on strength-based approaches and lists best practices for therapy practices in educational programs. The strength of this section is that, not only are all of these fundamental building blocks defined and described, they are described in a way that is sensitive to the daily challenges and demands faced by educators in real life settings.

Chapter two supplies concrete information useful for creating collaborative teams in schools. Christine Salisbury and Carl Dunst provide a framework for how to create home/school and community partnerships. They also cite empirical research, which supports family involvement, and emphasize family choices in types and levels of involvement. Useful ways to assess levels and types of involvement are incorporated into protocols educators may use when working with parents. One drawback of this chapter is that although it clearly delineates the major barriers to effective family/school partnerships (e.g. use of jargon, logistical constraints, educator biases), there are few concrete examples of how to overcome these barriers. Secondary level educators would undoubtedly like to have more information on how to operationalize "community" partnerships, but the chapter is strong in terms of early childhood and family involvement.

The second section of the book covers the implementation of the concepts and principles that make for effective education in the least restrictive environment. This section has four chapters, each summarizing a different component of educational programs: ecological curriculum, collaborative assessment, individualized education programs, and instructional design. Although much of this work was developed in the 1980's, the authors extensive experience in schools along with more recent empirical validation have refined our knowledge of "what works." Concrete examples and case studies are included that demonstrate how these concepts can be applied in practice.

The chapter entitled "An Ecological Model of Curriculum" contrasts developmental, functional and ecological approaches to developing educational programs for students with disabilities. Advantages and disadvantages of each approach are described based on research on effectiveness. For therapists trained in either the developmental or functional approaches this newer, more comprehensive (and sensible) way to frame what, where and how skills should be taught will be refreshing and enlightening. The authors provide a guide on how to develop goals, identify environments, prioritize activities and then how to conduct a component analysis of functional routines. Ten pages of "real life" examples and case studies portray how teachers and related service providers have designed successful ecological programs for students. In addition to knowing how to develop curriculum, practitioners need to know how to effectively evaluate their student's needs and skills. Conducting formal norm-referenced assessments in clinical settings provides little guidance when deciding what and how to teach students in natural settings. The chapter on assessment also provides information needed to conduct ecological inventories within natural settings. Formal assessment measures are reviewed from each of the disciplines (physical, occupational and speech/language therapy) that have been found to be useful for providing helpful information regarding skills and sub skills. Assessment information is included within the context of identifying the "best practices" for the provision of related services in schools. Examples of student IEPs, forms and procedures to connect assessment to collaborative instruction are also provided.

The last section of the book consists of two chapters that address strategies for implementing and evaluating collaborative teamwork. These short chapters are filled with ideas for how to go about doing the "systems change" work necessary to make collaboration a reality within educational services for students with severe disabilities. Much of this part is based on the work of Johnson and Johnson on effective team interaction. For the special educator or related service provider struggling to work within a hierarchical system these chapters will be a refreshing support and acknowledgement of needs faced by professionals. Different ways to solve problems such as scheduling dilemmas and disagreements among team members are presented. The last chapter is brief. It recognizes that organizational and personal changes are difficult, ambiguous and unsettling. But, it gives the practitioner the tools to implement change—and sustain it in productive ways. The text is well written and comprehensive. It provides the legal and philosophical rationale, descriptions of the "nuts and bolts" of effective service provision, and provides concrete strategies and resources necessary for building ecologically based, integrated programs within general educational settings. Special educators and related service providers will find this a welcome guidebook.

Reviewed by
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CHILDREN WITH FACIAL DIFFERENCE: A PARENT'S GUIDE

Hope Charkins
Woodbine House
$16.95, 361 pages, 1996

REVIEW

In her book, *Children with Facial Difference*, Hope Charkins strives to provide parents of children born with facial difference with easily accessible and understandable information to help them through the first stages of their child's life. Motivated by her own family's experiences following the birth of her son with Treacher Collins Syndrome (a condition characterized by facial difference), Charkins presents information in a manner intended to ease parents' current stress and prepare them for future situations by educating them about their child's condition. The impact of the new family member's unique needs on the child himself as well as on the family unit is addressed.

FACTUAL INFORMATION

Definitions of conditions, their causes, and lists of their common characteristics can help parents understand a child's diagnosis. In chapter one Charkins describes a variety of syndromes and other facial anomalies in easily understandable terms. She explains how particular characteristics might affect such functions as breathing, feeding, hearing, and speech.

Several medical procedures commonly used to improve functioning and/or appearance for children with facial difference are described. Charkins presents information about this subject with cautious optimism. Readers are advised of the improved functioning that procedures can bring, but are also made aware that simple answers might be based upon shallow understanding or uninformed judgments. It is important that the professionals involved in prescribing treatments be familiar with the child's specific condition and be in contact with other professionals involved with the child's care.

Charkins explains the team concept in treating cranial facial conditions and roles played by parents and professionals in the team process. Some of the professionals needed on a child's team could include medical doctors with various areas of expertise, dental specialists, feeding specialists, nutritionists, physical and/or occupational therapists, psychologists, speech/language pathologists, and social workers. The importance of parents as team members is emphasized when Charkins repeatedly encourages parents to be active members of the team. Lists of questions for parents to ask different professionals when determining who will work with their child are provided.

Additionally, Charkins provides insight into the range of emotional responses parents can expect to experience, their child's social and emotional development, and the experiences siblings of children with facial difference might encounter.

EMOTIONAL SUPPORT

The birth of a child with facial difference can cause parents to experience a myriad of emotions. Many parents are shocked to learn about (and see) a child with a facial difference especially if there is no know history of such a condition in the family. Denial is a common response after the initial shock has subsided. Emotions that follow can include (a) grief over the loss of the child the parents expected and the life they had envisioned for that child, (b) anger over such a loss and a perceived lack of support or insensitivity of others, (c) fear of what the future might hold for their child, or (d) about their own ability to deal with what is ahead. Stress between spouses is a common occurrence as well.

The birth of a child with facial difference into a family greatly changes life for other children in that family. Siblings might need help understanding the attention their brother or sister needs and in dealing with questions from friends (or strangers) about their sibling. Grandparents go through many of the same emotions parents experience when a child with facial difference is born.

Charkins offers suggestions to parents in responding to questions, stares, and other reactions from adults and children. She also addresses teaching the child and siblings how to respond in similar situations. An information sheet for people who will be involved with a child with facial difference is included. Charkins emphasizes the value of seeking support from a variety of sources. Psychologists and counselors can provide services for individuals or families dealing with adjustment to facial difference. Numerous service organizations are described in the book which Charkins encourages parents to contact for support for themselves and their families.

Coming to grips emotionally with a child's facial difference is a step toward reestablishing a routine family life. Charkins encourages parents to focus on their child's strengths and to maintain a healthy perspective. Family members need to realize that facial difference need not define a child or control the family. Most often, time will allow family members to accept the unique situation of a child with facial difference and assimilate such needs into a comfortable framework that functions for their family. As the family's comfort level increases, issues related to facial difference will become less daunting.

New challenges, however, arise at each milestone. Many of the challenges focus on factors outside the family and often include dealing with people who do not understand facial difference conditions. Parents who are knowledgeable about their child's condition will be better prepared to represent their child's needs in a variety of situations. Being informed about laws and entitlements that apply to their children will also help parents advocate effectively for their children.

BEING AN ADVOCATE

Charkins outlines some common reasons insurance companies cite for denying or reducing benefits to children with facial difference: exclusion of preexisting conditions, restrictions on treatment of secondary conditions, treatments not considered medically necessary, and inpatient or outpatient treatment exclusions. Parents must be knowledgeable of their insurance provisions, their child's condition and the treatment plan developed by the team of professionals caring for him or her.

Parents who are aware of laws that might help their children receive needed services will be better able to advocate for their children. The Individuals with Disabilities Education Act (IDEA) provides for special education and related services for children with disabilities. Facial difference is not defined as a disability itself, however, effects of a child's condition on hearing, speech, cognitive ability, daily living skills, and/or health related conditions might qualify a child for services under the IDEA. Charkins describes provisions of IDEA as well as rights provided under Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act.

Several national organizations provide information about facial difference to parents and can aid in advocacy efforts. Contact information for such organizations is provided.

CRITIQUE

Children with Facial Difference is a useful source of information and support for parents who are seeking information about facial difference conditions, their implications, and the impact a facial difference has on the life of the child and the child's family. The material Charkins presents in this book provides a strong foundation of information for parents who want to learn about facial difference conditions so they can better address their child's unique needs. The following features of *Children with Facial Difference* aid in building such a foundation.

1. Definitions and descriptions of conditions, treatments, laws, services, and assistive devices offered in clear, easily understandable terminology.
2. A 15 page glossary of terms.
3. Information about the roles of various professionals who commonly work with children with facial difference.
4. Description of the multidisciplinary team approach to treatment.
5. Practical information about what parents can expect with respect to their own emotions, other family members reactions and needs, treatment decisions, dealing with professionals or community members, and seeking services for their children.
6. Statements from parents of children with facial difference about their own experiences.
7. Lists of readings on topics presented in each chapter.
8. Resource guides including information about parent and professional organizations, educational issues, feeding, genetics, medical information, insurance, personal support, specialized toys, and disabilities.

Children with Facial Difference empowers readers by providing useful information for understanding facial difference conditions and determining realistic expectations of what life with and for children with facial difference can be. Parents and professionals alike will find this book a worthwhile resource, full of information that will enhance their ability to meet the needs of children with facial difference.

Reviewed by
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INFORMATION FOR AUTHORS

PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES
THE DIVISION FOR PHYSICAL AND HEALTH DISABILITIES

PDERS seeks to publish articles that contribute to the field of knowledge about education and related services for individuals with physical, orthopedic or health impairments. The following are considered for publication: empirical research; theoretical perspectives; case studies which address promising practices; innovative instructional practices; and reviews of relevant books, materials and software.

SUBMISSIONS

Manuscripts should be submitted to: Dr. Barbara J. Kulik, 3380 Country Club Drive, Glendale, CA 91208-1718 (bkulik@csun.edu). Three copies of the manuscript, together with a diskette or email attachment of the manuscript in either WordPerfect or MicrosoftWorks in IBM PC-compatible format, should be submitted for review. All tables and figures should be included with each copy of the manuscript.

PREPARATION

The entire manuscript (title page, abstract, text, tables, figures, and references) should be double-spaced on 8 1/2 x 11-inch paper with at least a 1-inch margin on all sides. A cover sheet should include title, author(s) name and affiliation (including statements of credit or research support), address, telephone number and email of the author to whom correspondence should be directed, and a running head. The abstract should precede the text on a separate sheet of paper and should bear the full title of the article. The running head should appear on all subsequent pages.

Tables and figures should be numbered by separate series and placed at the end of the manuscript. Provide brief notes within the text to indicate where each table or figure is to appear.

Overall style should conform to that described in the *Publication Manual of the American Psychological Association*, Fourth Edition, 1994.

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